

AD_____

Award Number: DAMD17-00-1-0215

TITLE: Aging Families and Breast Cancer: Multigenerational
Issues

PRINCIPAL INVESTIGATOR: Victoria H. Raveis, Ph.D.

CONTRACTING ORGANIZATION: Columbia University in the City
of New York
New York, New York 10032

REPORT DATE: July 2001

TYPE OF REPORT: Annual

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
Distribution Unlimited

The views, opinions and/or findings contained in this report are those of the author(s) and should not be construed as an official Department of the Army position, policy or decision unless so designated by other documentation.

20011203 051

REPORT DOCUMENTATION PAGEForm Approved
OMB No. 074-0188

Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503

| | | | | |
|--|---|--|---|--|
| 1. AGENCY USE ONLY (Leave blank) | | 2. REPORT DATE July 2001 | 3. REPORT TYPE AND DATES COVERED Annual (15 Jun 00 - 14 Jun 01) | |
| 4. TITLE AND SUBTITLE Aging Families and Breast Cancer: Multigenerational Issues | | | 5. FUNDING NUMBERS DAMD17-00-1-0215 | |
| 6. AUTHOR(S) Victoria H. Raveis, Ph.D. | | | | |
| 7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Columbia University in the City of New York New York, New York 10032 E-Mail: vhr1@columbia.edu | | | 8. PERFORMING ORGANIZATION REPORT NUMBER | |
| 9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012 | | | 10. SPONSORING / MONITORING AGENCY REPORT NUMBER | |
| 11. SUPPLEMENTARY NOTES | | | | |
| 12a. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited | | | | 12b. DISTRIBUTION CODE |
| 13. Abstract With the continuing shift of cancer care to community-based care the necessity to develop programs that will enable the family to meet patients' needs for support and assistance is of paramount importance. The overall purpose in conducting this exploratory investigation is to obtain information that will: identify adult daughter caregivers in need of psychosocial support interventions to enable them to meet their mothers' needs for illness-related emotional support and assistance; reduce daughters' emotional stresses associated with this support role, and, enable the daughters to continue their caregiving role. To accomplish these objectives we are collecting data from a sample of 80 older women (aged 60+) receiving treatment for breast cancer and their adult caregiving daughters. The patients and their daughters each complete a questionnaire. The daughters will also participate in a focused interview. Activities for Year 1 have focused on project start-up tasks, the initiation of the data collection effort and the establishment and implementation of data management procedures. To date, fifteen patient-daughter dyads have been accrued into the study. The activities initiated during Year 1 will be ongoing throughout Years 2 and 3. The data being collected will inform our understanding of psychosocial impact of cancer on the family. | | | | |
| 14. SUBJECT TERMS Psychosocial, aging family, informal caregiver, heredity risk, adaptation, social support | | | | 15. NUMBER OF PAGES 160 |
| | | | | 16. PRICE CODE |
| 17. SECURITY CLASSIFICATION OF REPORT Unclassified | 18. SECURITY CLASSIFICATION OF THIS PAGE Unclassified | 19. SECURITY CLASSIFICATION OF ABSTRACT Unclassified | | 20. LIMITATION OF ABSTRACT Unlimited |

NSN 7540-01-280-5500

Standard Form 298 (Rev. 2-89)
Prescribed by ANSI Std. Z39-18
298-102

Table of Contents

| | |
|-----------------------------------|----|
| Cover..... | 1 |
| SF 298..... | 2 |
| Table of Contents..... | 3 |
| Introduction..... | 4 |
| Body..... | 4 |
| Key Research Accomplishments..... | 11 |
| Reportable Outcomes..... | 12 |
| Conclusions..... | 12 |
| References..... | 12 |
| Appendices..... | 13 |

INTRODUCTION

Life expectancy has increased dramatically in recent decades, producing an equally impressive expansion in the size of the elderly population. However, little attention has been given to cancer in the aged. Even less is known about the psychosocial problems experienced by older breast cancer patients and their families as very little empirical research has focused on understanding the dynamics of older women's support networks. In particular, adult daughters, who are likely to be a primary source of support and assistance to older women, have not been a focus of research investigations or supportive services although they are likely to be experiencing a high demand for emotional support themselves. The overall purpose in conducting this exploratory investigation is to obtain information that will: identify adult daughter caregivers in need of psychosocial support interventions to enable them to meet their mothers' needs for illness-related emotional support and assistance; reduce daughters' emotional stresses associated with this support role, and, enable the daughters to continue their caregiving role. To accomplish these objectives we will be collecting data from a sample of 80 older women (aged 60+) receiving treatment for breast cancer and their adult caregiving daughters. The patients and their daughters each complete a questionnaire. The daughters will also participate in a focused interview. The activities for Year 1 have adhered to the research accomplishments scheduled for Year 1 in the Statement of Work. Specifically, Year 1 activities have focused on project start-up tasks, the initiation of the data collection effort and the establishment and implementation of data management procedures. To date, fifteen patient-daughter dyads have been accrued into the study. The activities initiated during Year 1 will be ongoing throughout Years 2 and 3.

BODY

The activities conducted during Year 1 have adhered to the approved Statement Of Work. Overall, the research accomplishments that were scheduled to be completed in Year 1 (i.e., Tasks 1-4) have been completed. Other tasks (i.e., Tasks 5-7) that were scheduled to be initiated in Year 1, but continued into Years 2-3, have been initiated. The specific details are provided below, organized by task.

Task 1: Obtain access and prepare case accrual, Months 1-3

- a. Institutional Review Board approval obtained from hospital site*
- b. Medical record abstract forms prepared*
- c. Field materials (screening forms, accrual letters, etc.) for accrual and data collection of patient/daughter cases developed*
- d. Spanish version of field materials translated and back-translated*

A major task during Year 1 was the performance of a wide variety of start-up activities necessary to obtain access to the patient population and initiate outreach and accrual of the patient-daughter accrual. The key activities outlined under Task 1 were successfully conducted during Year 1.

The study has been reviewed by the Herbert Irving Comprehensive Cancer Center protocol office and approved. The Columbia University Institutional Review Board has also reviewed and approved the study protocol. Copies of the approval letters and annual renewal of study protocol approval are included in Appendix A. A variety of field materials necessary for sample identification, outreach and accrual have been prepared. These include the medical record abstract form (Appendix B), patient-daughter screening eligibility form (Appendix D), patient and daughter recruitment letters (Appendix C), daughter consent form (Appendix E), physician permission form and telephone contact sheet (Appendix D). Spanish versions of the relevant patient and daughter field materials have been developed and are included in appendices referenced above.

Task 2: Prepare patient and daughter questionnaire collection, Months 1- 4

- a. Patient and caregiving daughter questionnaires prepared*
- b. Spanish version of patient and caregiving daughter questionnaires translated and back-translated*
- c. English and Spanish versions of patient and daughter questionnaires pre-tested and finalized*
- d. Research clinician interviewers trained in field procedures and administration of questionnaires*

The questionnaires that the daughter and her mother will complete were finalized in Year 1. These questionnaires are described below.

(a) Daughter questionnaire. Standard sociodemographics and lifestyle data are being obtained. Daughters report on the quality of the mother/daughter relationship and its change since the patient's cancer diagnosis, using an abbreviated version of the Network of Relationships Inventory [1]. They complete a four-item perceived predictability of illness measure (4 items from the Mishel Uncertainty in Illness Scale [2]), a six-item measure of perceived personal control over the illness [3], the Center for Epidemiological Studies of Depression scale (CES-D), a widely used, validated and reliable 20-item measure of depressive symptomatology [4] and the 20-item State Anxiety Scale (STAI-S), a widely used, validated and reliable measure of anxiety [5]. Daughters report on caregiving consequences in five burden domains -- physical, time, employment, financial, and social [6]. They complete measures of caregiving responsibilities [7] and caregiving commitment [8]. Daughters also complete the Impact of Event Scale (IES) [9]. They provide information on family history of breast cancer, age at menarche, childbearing history, history of breast biopsies and age at biopsies. Their perceived risk of developing breast cancer will be assessed using 4 items taken from previous studies of women at increased risk for the disease [10,11]. Daughters are asked about their practice of breast self-examination and their use of mammogram and clinical breast exams. A copy of the daughter questionnaire (English/Spanish) is contained in Appendix G.

(b) Patient questionnaire. Patients are also being asked standard sociodemographic and

lifestyle data. They report on the quality of the mother/daughter relationship and its change since their cancer diagnosis, using an abbreviated version of the Network of Relationships Inventory [1]. Patients complete the four-item perceived predictability of illness measure (from the Mishel Uncertainty in Illness Scale [2]), the six-item measure of perceived personal control over the illness [3], the Center for Epidemiological Studies of Depression scale (CES-D) [4] and the 20-item State Anxiety Scale (STAI-S) [5]. Patients report their need for support/assistance with activities of daily living (ADLs) and other illness-related tasks, as well as the formal and informal provider(s) of assistance [12]. A copy of the patient questionnaire (English/Spanish) is contained in Appendix F.

Also during Year 1, the Spanish version of the patient and caregiving daughter questionnaires were prepared. Both the English and Spanish versions of the patient and daughter questionnaires were finalized after careful review and pre-testing. Prior to the initiation of the data collection, the research clinician interviewers were trained in the field procedures and the appropriate administration of the daughter and patient questionnaires.

Task 3: Prepare focused interview data collection, Months 2-4

- a. Topic guide finalized for focused interviews*
- b. Research clinician interviewers trained in focused interview techniques*
- c. Interviewers conduct initial focused interviews for review and critique*

During Year 1, the topic guide for the focused interview with the caregiving daughter was finalized. A copy is contained in Appendix H. Topics the daughter is being queried about include: circumstances leading to her assumption of caregiving, her reactions to her mother's illness and treatment, her level of caregiving involvement, changes in her relationship with her mother since the illness/involvement in caregiving, her assessment of her mother's support needs and her evaluation of her caregiving and support provision. The daughter is also being asked to talk about her perceived vulnerability to cancer and the personal risk factors she believes she has. Availability and adequacy of her own support, as it relates to her caregiving and personal cancer concerns is also being explored.

Prior to conducting the focused interviews, the research clinician interviewers were trained in focused interview techniques. The initial focused interviews they conducted were reviewed and critiqued to ensure that the interviewer adhered to the study protocol. Throughout the data collection period, the interviewers will be monitored on an ongoing basis to maintain quality and consistency in the conduct of the focused interview. Additional training will be provided as needed.

Task 4: Design data management procedures, Months 3-8

- a. Procedures manual prepared*
- b. Research assistant trained in editing, coding, data entry techniques*

- d. *Coding manual developed*
- f. *Data entry computer programs established*

During Year 1, another important body of activities that were performed as part of the project start-up tasks were activities initiated to ensure appropriate data management. These tasks include the establishment of the project data management procedures, including documents outlining the editing and coding guidelines. A variety of data management computer programs were created during Year 1 as well. These include an ACCESS database reflecting physician permission status, an ACCESS database for sample recruitment screener forms, an ACCESS database for patient medical data, a patient questionnaire SPSS data entry program, and a daughter questionnaire SPSS data entry program. The research assistant on the project was then trained in the editing, coding, data entry protocol for the study.

Task 5: Subject recruitment and data collection, Months 4-30

- a. *Potentially eligible cases identified from ongoing review of clinic and hospital records*
- b. *Potentially eligible patient-daughter dyads contacted, screened and accrued*
- c. *Begin collecting questionnaire data from patient-daughter dyads*
- d. *Begin conducting focused interviews with caregiving daughters*

Throughout Years 1-3, a sample consisting of 80 older women (aged 60+) receiving treatment for breast cancer and their adult caregiving daughters will be accrued. Potentially eligible patients are being identified from an ongoing review of the breast cancer patient population at the Herbert Irving Comprehensive Cancer Center, whose catchment area includes diverse socioeconomic and racial/ethnic neighborhoods. Permission to approach potentially eligible patients (i.e., diagnosed with breast cancer, in active treatment, aged 60+) is obtained from the patient's physician. Once permission is received these patients are sent a letter informing them about the study. A return post card with a check-off for persons who do not wish to be contacted is included with the letter. A clinician researcher then contacts them by telephone to discuss the study further, determine their eligibility and, if they are interested in participating, determine whether the patient has a caregiving daughter who is 21+, a biological daughter, not have a history of cancer and be involved in providing practical assistance and support to the patient. The clinician researcher then obtains permission from any patient, who is eligible and interested in the study, to contact the daughter for study participation. The daughter is then be sent a letter, followed by a phone conversation with the clinician researcher about the study. Only those patient-daughter dyads in which both members are willing to participate are accrued.

In Table 1 the distribution by eligibility and participation status of the pool of potentially-eligible patient cases identified in Year 1 are shown. As can be seen the eligibility status of 39% of the patient pool could not be determined, primarily due to patient refusal to be contacted (n=26) or to be screened (n=13). For an additional 13 cases, the patient was unable to be reached, and in one instance the patient died prior to being contacted.

**Table 1: Elderly Breast Cancer Patients Contacted in Year 1 by
Eligibility and Participation Status (N=136)**

| | <u>%</u> | <u>(n)</u> |
|---|----------|------------|
| Eligible patient-daughter dyads (n=26): | | |
| Patient & daughter accrued | 11 | 15 |
| Patient agreed, daughter refused | 7 | 10 |
| Patient agreed, daughter died prior to accrual | 1 | 1 |
| Ineligible patient-daughter dyads (n=57): | | |
| Patient resides outside U.S., in U.S. to receive treatment | 1 | 1 |
| Patient does not have a daughter | 29 | 39 |
| Patient has a daughter, but daughter does not provide caregiving to patient | 13 | 17 |
| Unknown eligibility (n=53): | | |
| Patient refused contact, returned postcard checking off option stating "DO NOT CONTACT" | 19 | 26 |
| Patient refused to complete screener form | 10 | 13 |
| Telephone disconnected, incorrect number, no answer following repeated attempts | 10 | 13 |
| Patient died prior to screening | 1 | 1 |

In Year 1, from the pool of patients interested in the study (61%), about two-thirds of these patients were determined to be ineligible for the study. The major reason that a patient was ineligible was that she did not have a daughter (n=39). The second ineligibility reason was that the patient's daughter was not a caregiver to the mother (n=17). There was also one case in which the patient did not reside in the U.S. permanently and was only in residence while receiving treatment for her breast cancer. Generally, once an eligible patient was identified, the daughter was also found to be interested in participating in the study. About three-fifths of the eligible patient-daughter dyads agreed to participate in the study (n=15).

The project start-up activities specified in Tasks 1-4 took longer to complete than initially projected and the initiation of accrual and data collection was started slightly later in the year than anticipated. Although it was originally projected that 20 patient-daughter dyads would have been accrued by the end of Year 1, we were able to accrue 15 dyads. Consequently, by the end of Year 1, 15 patient questionnaires were completed, 14 daughter questionnaires were completed and 14 focused interviews were conducted.

In Table 2 is shown the distribution of the patient sample (n=15) that have been accrued into the study during Year 1. In keeping with the racial and ethnic mix of the hospital catchment area, 60% of the patients are white, 33% are Hispanic and 7% are black. The majority of the patients are currently married, 40%. Another third are widowed, and 20% are divorced or separated. Most of the patients are elderly. One-third are 60-69 years old, 47% are 70-79 and 20% are 80 or older. Two-thirds of the patients have been diagnosed with local breast cancer. While all of the patients have received surgery for their cancer, one third of the patients have also had radiation and one-fifth have had chemotherapy.

Task 6: Data processing of qualitative (questionnaire) data, Months 6-30

- a. Patient and daughter questionnaires edited, coded and data entered into computer databases*
- b. Data cleaning of questionnaire data implemented*

Once a questionnaire has been completed, the questionnaire is edited and coded, then the responses are entered in a computer database. As part of the data entry program a variety of data cleaning and data checking procedures have been written into the program. This ensures that out-of-range punches, miscodes and "Does not apply" sections are identified and errors are corrected.

Task 7: Coding and textual analysis of qualitative (focused interview) data, Months 10-33

- a. Transcripts of audiotaped focused interviews entered into computer text files*

The focused interviews that are being conducted with the daughter are audiotaped, with the

**Table 2: Sociodemographics of Elderly Breast
Cancer Patient Sample in Year 1 (N=15)**

| | <u>%</u> | <u>(n)</u> |
|----------------------------------|----------|------------|
| Race/Ethnicity: | | |
| White | 60 | 9 |
| Hispanic | 33 | 5 |
| Black | 7 | 1 |
| Marital Status: | | |
| Married | 40 | 6 |
| Widowed | 33 | 5 |
| Divorced | 13 | 2 |
| Separated | 7 | 1 |
| Never married | 7 | 1 |
| Age: | | |
| 60-69 | 33 | 5 |
| 70-79 | 47 | 7 |
| 80-89 | 20 | 3 |
| Extent of Cancer: | | |
| Local | 67 | 10 |
| Regional/Metastatic | 33 | 5 |
| Type of Cancer Treatment: | | |
| Surgery | 47 | 7 |
| Surgery & Radiation | 33 | 5 |
| Surgery & Chemotherapy | 20 | 3 |

daughter's permission. These audiotapes are then transcribed and entered into computer text files for later analysis and textual coding. Once twenty cases have been transcribed, the development of a provisional textual coding scheme will begin.

KEY RESEARCH ACCOMPLISHMENTS

- Obtained IRB approval for study protocol [Appendix A]
- Finalized sample (patient & daughter) recruitment letters [Appendix C]
- Translated recruitment letters in Spanish [Appendix C]
- Finalized daughter consent forms [Appendix E]
- Translated daughter consent forms into Spanish [Appendix E]
- Finalized data collection forms:
 - Patient and daughter screener form [Appendix D]
 - Patient questionnaire [Appendix F]
 - Daughter questionnaire [Appendix G]
 - Daughter focused interview guide [Appendix H]
- Finalized Spanish translation of data collection forms:
 - Spanish translation of Patient questionnaire
 - Spanish translation of Daughter questionnaire
- Finalized physician recruitment letter
- Elicited physician cooperation for patient recruitment
- Created ACCESS database reflecting physician permission status
- Created ACCESS database for sample recruitment screener forms
- Created ACCESS database for medical record forms
- Initiated patient-daughter dyad accrual
- Trained clinician interviewer in data collection techniques
- Initiated data collection with patients and daughters
- Conducted 15 patient telephone interviews (structured questionnaire)
- Conducted 14 daughter face-to-face interviews (structured questionnaire and focused interview)
- Created patient questionnaire SPSS data entry program
- Created daughter questionnaire SPSS data entry program
- Established editing and coding procedures for patient and daughter questionnaires
- Edited, coded and data entered patient and daughter questionnaires
- Created SPSS systemfile for patient questionnaires
- Created SPSS systemfile for daughter questionnaires
- Transcribed daughter focused interviews
- Created archive database of daughter focused interview transcripts

REPORTABLE OUTCOMES

Year 1 reportable outcomes are the establishment of the databases that will continue to expand as more patient-daughter dyads are accrued and interviewed throughout Years 2-3. The specific databases are listed below:

- SPSS systemfile of patient questionnaire data (n=15)
- SPSS systemfile of daughter questionnaire data (n=14)
- Archive database of word processed transcripts of daughter focused interviews (n=14)

CONCLUSIONS

The Year 1 field experiences reaffirm the feasibility of the study procedures (i.e., case identification, sample accrual and data collection) that were proposed in the grant application. Although there was a slight delay in initiating the sample recruitment, due to a longer start-up period, the data collection effort is underway. It is expected that project activities will continue to proceed as outlined in the Statement Of Work for Years 2 and 3..

REFERENCES

1. Furman, W. (1996). The measurement of friendship perception: Conceptual and methodological issues. In W. M. Bukowski, A. F. Newcomb, & W. W. Hartup (Eds.). Company they keep: Friendships in childhood and adolescence. New York: Cambridge University Press.
2. Mishel, M. H. (1981). The measurement of uncertainty in illness. Nursing Research, 30, 258-263.
3. Affleck, G., Tennen, H., Pfeiffer, C., & Fifield, J. (1987). Appraisals of control & predictability in adapting to a chronic disease. J of Personality & Social Psychology, 53:273-279.
4. Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. Applied Psychological Measurement, 1, 385-401.
5. Spielberger, C. D. (1983). Manual for the State-Trait Anxiety Inventory (Form Y). Palo Alto, CA.
6. Raveis, V. H., Karus, D. & Siegel, K (1998) Correlates of depressive symptomatology among adult daughter caregivers to a parent with cancer. Cancer, 83(8), 1652-1663.
7. Raveis, V. H., Karus, D. & Pretter, S. (1999) Factors associated with anxiety in adult daughter caregivers to a parent recently diagnosed with cancer. Journal of Psychosocial Oncology, 17(3/4): 1-26.
8. Given, C. W, Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The Caregiver Reaction Assessment (CRA) for caregivers to persons with

- chronic physical and mental impairments. Research in Nursing and Health, 15, 271-283.
9. Horowitz, M., Wilner, N., & Alvarez, W. (1979). Impact of Event Scale: A measure of subjective stress. Psychosomatic Medicine, 41, 209-218.
 10. Schwartz, M. D., Lerman, C., Miller, S. M., Daly, M., & Masny, A. (1995). Coping disposition, perceived risk, and psychological distress among women at increased risk for ovarian cancer. Health Psychology, 14, 232-235.
 11. Croyle, R. T., Smith, K. R., Botkin, J. R., Baty, B., & Nash, J. (1997). Psychological responses to BRCAI mutation testing: Preliminary findings. Health Psychology, 16, 63-72.
 12. Raveis, V. H., & Karus, D (1999) Elderly cancer patients: Correlates of depressive symptomatology. Journal of Psychosocial Oncology, 17(2) 57-77.

APPENDICES

| <u>Appendix</u> | <u>Title</u> |
|-----------------|--|
| A | Columbia University Study Protocol Approval Letters |
| B | Medical Records Form |
| C | Patient and Daughter Recruitment Letters (English/Spanish) |
| D | Patient-Daughter Telephone Contact Log and Screener Form |
| E | Daughter Informed Consent Form (English/Spanish) |
| F | Patient Questionnaire (English/Spanish) |
| G | Daughter Questionnaire (English/Spanish) |
| H | Focused Interview Topic Guide |

APPENDIX A

Columbia University Study Protocol Approval Letters



HERBERT IRVING COMPREHENSIVE CANCER CENTER

Columbia University
Clinical Protocol Office

March 21, 2000

Victoria Raveis, M.D.
100 Haven Ave
Suite 6A

Re: IRB# pending (CPMC): Aging Families and Breast Cancer.

Dear Dr. Raveis:

Thank you for your letter dated February 23, 2000 regarding the above noted protocol. The issues raised by the Cancer Center Protocol Review Committee have been addressed. Therefore, the study has now been approved.

As you know, final IRB approval will be required before you can enroll patients or collect data

Sincerely,

Elizabeth Kaufman, M.P.H.
Director

EK/lb

cc: L Dean
IRB

COLUMBIA UNIVERSITY
COLLEGE OF PHYSICIANS & SURGEONS

COLUMBIA-PRESBYTERIAN MEDICAL CENTER INSTITUTIONAL REVIEW BOARD
CPMC IRB

DATE: June 5, 2001

TO: Victoria Raveis, PhD
School of Public Health
100 Haven Ave Ste 6A (Tower 2)

FROM: Office of the Institutional Review Board

**RE: CPMC IRB #9585 "AGING FAMILIES AND BREAST CANCER:
MULTIGENERATIONAL ISSUES"**

Dear Dr. Raveis:

The Institutional Review Board at the May 23, 2001 convened meeting reviewed and approved your request for the Annual Grant Review of the above referenced research project. The Board approved the continuation of the research project for the period of May 2, 2001 to March 28, 2002.

A request for continuation or completion of the study protocol is due at least 30 days before the project expiration date of March 28, 2002, unless otherwise requested by the Board. Please remember that any proposed changes to research activity and/or adverse events associated with this research project are require to be reported promptly to the Institutional Review Board.

Sincerely,



Paul Papagni, JD
Executive Director, CPMC IRB

PP/gad

Project Expiration Date: March 28, 2002

APPENDIX B

Medical Records Form

PATIENT DEMOGRAPHICS

1. Patient's Age: _____
 2. Patient's Sex: 1-Male 2-Female
 3. Patient's Race/Ethnicity:
 - 1-White
 - 2-Black
 - 3-Asian/Pacific Islander
 - 4-American Indian/Alaskan Native
 - 5-Hispanic
 - 6-Other
 - 7-Not Available
 4. Patient's Marital Status
 - 1-Married
 - 2-Living with a Partner
 - 3-Divorced
 - 4-Seperated
 - 5-Widowed
 - 6-Never Married
-

PATIENT'S MEDICAL INFORMATION

5. Cancer Site: _____
6. Treatment Undergone:
 - 1-Surgery
 - 2-Radiation
 - 3-Chemotherapy
 - 4-Surgery & radiation
 - 5-Surgery & Chemotherapy
 - 6-Radiation & Chemotherapy
 - 7-Surgery, Radiation & Chemotherapy
 - 8-Other
 - 9-Has Not Undergone any Type of Treatment

APPENDIX C

Patient and Daughter Recruitment Letters (English/Spanish)

| | | | |
|--------------------------------------|--------------------|-----------------|---------|
| Institutional Review Board (CPMCIRB) | | | |
| IRB # | 9585 | Approval Date | 5/2/01 |
| Initials | <i>[Signature]</i> | Expiration Date | 3/28/02 |
| Columbia Presbyterian Medical Center | | | |

Date

Patient's Name

Street Address

City, State, Zip Code

Dear Ms./Mrs. *Patient's Name*:

We are writing to ask you to participate in a research study that researchers at the Herbert Irving Comprehensive Cancer Center and Columbia University, Mailman School of Public Health are conducting. The name of the study is "Aging Families and Breast Cancer: Multigenerational Issues". Its' purpose is to investigate the illness and treatment-related issues patients diagnosed with breast cancer and their care giving daughters are experiencing. We have spoken with Dr. *Patient's Physician* about this study and *he/she* thinks you may be interested in taking part.

In a few days, a social worker on the study will be calling you to discuss the study further and answer any questions you might have. If you do not want to be called, check-off the "Do not contact" box on the enclosed postcard and mail it back to our office. If you are interested in this study, the social worker will ask you a few, brief questions about yourself and your illness to see if you and your daughter are eligible to participate in the study. If you are, both of you will be asked to complete an interview. The interview will be conducted by a member of our research team. In this interview we will ask you about your illness and needs for assistance. We will also ask you some background questions about yourself. You can choose not to answer any question. Your interview will be conducted by telephone at a time that is convenient to you. It will take about 40 minutes. We will also be interviewing your daughter about her care giving experiences and how your illness and its treatment has affected her.

What you tell us in this interview will be kept strictly confidential. It will only be used for the present study and the information you provide will only be seen by the investigators carrying out the research. All study data will be assigned a unique code number and kept in locked file cabinets in our research offices. Your doctor will not know that you agreed to participate in the study. This study has been funded by the Department of Defense. Representatives from the U.S. Army Medical Research and Materiel Command are eligible to inspect the records of this research as part of their responsibilities to protect human subjects in research.

If you decide not to participate in this study, your decision will in no way affect the medical or other services you are receiving now or in the future. If you do decide to participate, you can decide to stop participating at any time. There will be no penalty or loss of benefits to which you are entitled. There are no physical risks or cost to you for participating in the study. You will not receive any payment for the interview. Talking with the research clinician may cause you to confront some sensitive feelings and issues related to your illness and its treatment. For this reason, the interviewer is an experienced clinician who has been trained to address any such distress. Although you may not benefit directly from this study, we feel that what you and your

| | |
|--------------------------------------|-------------------------|
| Institutional Review Board (CPMCIRB) | |
| IRB # 9585 | Approval Date 5/2/01 |
| Initials <i>VC</i> | Expiration Date 3/28/02 |
| Columbia Presbyterian Medical Center | |

daughter will tell us about your experiences will help other patients and their families in the future.

If at anytime you need any additional information, you may call me (Victoria H. Raveis, Ph.D.) at (212) 304-5566. The solicitation of subjects into this study has been approved by the Columbia Presbyterian Medical Center Institutional Review Board. If you have any questions about your rights as a research subject, you can call the Institutional Review Board at (212) 305-5883 for information.

The choice to participate in this study is yours. You are in a position to make a decision if you understand what you have read in this letter about the study. Your participation in the research interview will be regarded as evidence of your consent to participate. You will not be asked to sign a consent form. If you agree to the interview, you still have a right to stop at any time.

Sincerely,

Victoria H. Raveis, Ph.D.
Associate Professor of Clinical Public Health

cc: Patient's Physician

Date

Daughter's Name
Street Address
City, State, Zip Code

Dear Ms./Mrs. *Daughter's Name*:

We are writing to ask you to participate in a research study that researchers at the Herbert Irving Comprehensive Cancer Center and Columbia University, Mailman School of Public Health are conducting. The name of the study is "Aging Families and Breast Cancer: Multigenerational Issues". Its purpose is to investigate the illness and treatment-related issues patients diagnosed with breast cancer and their care giving daughters are experiencing. We have spoken with your mother about this study and she has told us how to contact you.

In a few days a social worker on the study will be calling you to tell you more about this study and answer any questions you may have. If you decide to participate in this study we are asking you to participate in a two and one-half hour face-to-face research meeting with a research clinician. This research meeting will be scheduled at your convenience. It will be held at our research offices at 100 Haven Avenue, about three blocks away from the hospital.

In the first part of the meeting you will be asked to answer a questionnaire that will contain questions about your mother's illness, treatment experiences and needs for assistance. We will also ask you about your care giving and some background questions about yourself. In the second part of the research meeting, we will ask you to tell us in greater detail about how your mother's illness and its treatment has impacted on your life. We will also ask you about other illness-related issues and concerns you may have. With your permission we will tape record this part so that it can be typed up and analyzed.

If you decide not to participate, your decision will in no way affect the medical or other services your mother is receiving now or in the future. The choice to participate in this study is yours. You are in a position to make a decision if you understand what you have read in this letter about the study. If you agree to the interview, you still have a right to stop at any time.

If at anytime you need any additional information, you may call me (Victoria H. Raveis, Ph.D.) at (212) 304-5566. The solicitation of subjects into this study has been approved by the Columbia Presbyterian Medical Center Institutional Review Board. If you have any questions about your rights as a research subject, you can call the Institutional Review Board at (212) 305-5883 for information.

Sincerely,

Victoria H. Raveis, Ph.D.
Associate Professor of Clinical Public Health

Date

Patient's Name
Street Address
City, State, Zip Code

Estimada *Patient's Name*:

Le escribimos para solicitar su participación en una investigación conducida por el Centro Herbert Irving para el Tratamiento del Cáncer y la Escuela Mailman de Salud Pública de la Universidad de Columbia. El nombre del estudio es "Envejecimiento de familiares y cáncer del seno: problemas multigeneracionales". El objetivo del estudio es investigar los problemas relacionados con la enfermedad y el tratamiento de las pacientes diagnosticadas con cáncer del seno y las experiencias de sus hijas que las atienden. Hablamos con el/la Dr (a). *Patient's Physician* de este estudio y él/ella cree que usted puede estar interesada en participar en el estudio.

En unos días, un trabajador social de esta investigación le llamará para hablar del estudio con más detalle y contestarle cualquier pregunta que usted tenga. Si usted no quiere recibir una llamada, marque la caja que dice "No me contacte" en la postal que incluimos y envíela a nuestra oficina. Si le interesa este estudio, el trabajador social le hará unas breves y pocas preguntas acerca de usted y de su enfermedad para determinar si usted y su hija son elegibles para participar en el estudio. Si resultan elegibles, se les pedirá a ambas que realicen una entrevista. La entrevista la llevará a cabo un miembro de nuestro equipo investigativo. En esta entrevista le haremos a usted preguntas sobre su enfermedad y la necesidad de ayuda. También le haremos algunas preguntas con respecto a su historial. Tiene la opción de no contestar a ninguna pregunta. La entrevista se realizará por teléfono a una hora que le sea conveniente a usted. La entrevista tomará como 40 minutos. Entrevistaremos a su hija sobre sus experiencias como proveedora de asistencia y cómo su enfermedad y el tratamiento le han afectado.

Lo que usted nos revele durante la entrevista se mantendrá completamente confidencial. La información se usará solamente para el estudio actual y se dará a conocer solamente a los investigadores responsables de este estudio. Se le asignará un código numérico único a los datos del estudio y se guardarán en archivos bajo llave en nuestras oficinas de la investigación. Su médico no va a saber de su participación. El Departamento de Defensa dio los fondos para este estudio. Los representantes del Army Medical Research and Materiel Command de los Estados Unidos son elegibles para revisar los expedientes de esta investigación como parte de sus responsabilidades de proteger a los seres humanos en una investigación.

Si usted decide que no quiere participar, su decisión no afectará de ningún modo a su cuidado médico ni a cualquier otro servicio que esté recibiendo ni ahora ni en el futuro. Si usted decide participar, puede dejar de participar en cualquier momento. No habrá ninguna penalidad ni pérdida de beneficios a los cuales usted tenga derecho. Su participación en este estudio no llevará ningún riesgo físico ni habrá costo para usted. No va a recibir ningún dinero por la entrevista. El hablar con un clínico de la investigación puede hacer que tenga algunas emociones relacionadas con problemas

Reviewed by: *MG 06-07-01*
The Hispanic Research and Recruitment Center
Columbia-Presbyterian Medical Center

y sentimientos sobre la enfermedad y el tratamiento. Por esta razón, la persona encargada de conducir la entrevista es un clínico con experiencia que ha recibido entrenamiento para manejar cualquier sentimiento de angustia. Aunque usted tal vez no se beneficie directamente de su participación en este estudio, tenemos confianza de que lo que usted y su hija nos diga sobre sus experiencias ayudará a otras pacientes y a sus familias en el futuro.

Si usted necesita más información en cualquier momento, puede llamarme (Victoria H. Raveis, Ph.D.) al (212) 304-5566. La solicitud de personas para participar en esta investigación ha sido aprobada por La Comisión Institucional de Revisión del Centro Médico de Columbia Presbyterian. Si usted tiene alguna pregunta sobre sus derechos como sujeto de una investigación, podrá llamar a La Comisión Institucional de Revisión al (212) 305-5883.

La decisión de participar en este estudio es suya. Usted puede tomar una decisión si comprende lo que ha leído en esta carta con respecto al estudio. Su participación en las entrevistas investigativas será considerada como evidencia de su consentimiento a participar. No se le pedirá que firme un formulario de consentimiento. Si usted está de acuerdo con la entrevista, aún tendrá el derecho de retirarse en cualquier momento.

Atentamente,

Victoria H. Raveis, Ph.D.
Profesora Asociada de
Salud Pública Clínica

cc: *Patient's Physician*

Date

Daughter's Name
Street Address
City, State, Zip Code

Estimada *Daughter's Name*:

Le escribimos para pedir su participación en una investigación conducida por el Centro Herbert Irving para el Tratamiento del Cáncer y la Escuela Mailman de Salud Pública de la Universidad de Columbia. El nombre del estudio es "Envejecimiento de familiares y cáncer del seno: problemas multigeneracionales". El objetivo del estudio es investigar los problemas relacionados con la enfermedad y el tratamiento de las pacientes diagnosticadas con cáncer del seno y las experiencias de sus hijas que las atienden. Hablamos con su madre sobre este estudio y ella nos dijo cómo contactar con usted.

En unos días, un trabajador social de esta investigación le llamará para hablar de este estudio con más detalle y contestarle cualquier pregunta que usted pueda tener. Si usted está de acuerdo en participar, le pediremos que participe en una entrevista frente a frente con un clínico de la investigación. Esta entrevista dura dos horas y media. La entrevista se programará a una hora que le sea conveniente a usted y se llevará a cabo en nuestras oficinas localizadas en 100 Avenida Haven, casi a tres cuadras del hospital.

En la primera parte de la entrevista, le pediremos que conteste un cuestionario que tiene preguntas sobre la enfermedad de su madre, las experiencias del tratamiento y la necesidad de ayuda. También se le harán preguntas con respecto al cuidado que usted brinda a su madre, y algunas preguntas sobre su propio historial. En la otra parte de la entrevista, le pediremos que nos diga con más detalle cómo la enfermedad y el tratamiento de su madre le han impactado. También se le harán preguntas sobre otros problemas relacionados con la enfermedad y preocupaciones que pueda tener usted. Con su permiso, grabaremos su información para escribirla a máquina y analizarla.

Si usted decide no participar, su decisión no afectará de ningún modo al cuidado médico ni a otros servicios que su madre está recibiendo ni ahora ni en el futuro. La decisión de participar en este estudio es suya. Usted puede tomar una decisión si comprende lo que ha leído en esta carta con respecto al estudio. Si usted está de acuerdo con participar en la entrevista, aún tiene derecho de retirarse en cualquier momento.

Reviewed by: MG 06-07-01
The Hispanic Research and Recruitment Center
Columbia-Presbyterian Medical Center

Si usted necesita más información en cualquier momento, puede llamarme (Victoria H. Raveis, Ph.D.) al (212) 304-5566. La solicitud de personas para participar en esta investigación ha sido aprobada por La Comisión Institucional de Revisión del Centro Médico de Columbia Presbyterian. Si usted tiene alguna pregunta sobre sus derechos como participante en un investigación, podrá llamar a La Comisión Institucional de Revisión al (212) 305-5883.

Atentamente,

Victoria H. Raveis, Ph.D.
Profesora Asociada de
Salud Pública Clínica

APPENDIX D

Patient-Daughter Telephone Contact Log and Screener Form

TELEPHONE CONTACT SHEET

Contact# «Contact»

Date Letter Sent: «Date_Letter_Sent»

Patient's Name: «FirstName» «LastName»

Patient's Address: «Address»
«City», «State» «ZipCode»

Home Phone #: «HomePhone» Work Phone #: «WorkPhone»

MRN: «MRN»

Doctor: «Doctor»

Pt List #: «Pt_List»

LOG OF PHONE CALLS AND CONTACTS

Record Results As:

| | | |
|----------------------|---------------------|-----------------------------|
| 1-no answer | 4-answering machine | 7-person delegate contacted |
| 2-busy | 5-person not there | 8-patient initiated contact |
| 3-phone disconnected | 6-person contacted | 9-do not contact* |

| # | DATE | TIME | RESULTS |
|----|------|------|---------|
| 1. | | | |
| 2. | | | |
| 3. | | | |
| 4. | | | |
| 5. | | | |
| 6. | | | |
| 7. | | | |

1. Was a screener form filled out? a-Yes b-No (If No, Why?)

1-postcard returned*
2-person refused
3-person died
4-unable contact/eligibility period expired
5-doesn't speak English/Spanish
6-foreign address
7-other: _____

2. Person who did the screening: _____

AGING FAMILIES & BR CA

ID # _____

Screening#

AGING FAMILIES AND BREAST CANCER SCREENER

1. Do you have a biological daughter?

BRSCR1

1-Yes

2-No

Comments: _____

2. How often does she see or visit you?

BRSCR2

1-Daily

2-Several times a week

3-Once a week

4-A couple of times a month

5-Once a month

6-A few times a year

Comments: _____

3. When people are ill, family members often help out with a variety of activities.

BRSCR3

Since your diagnosis, has your daughter been helping you with your day-to-day activities, such as helping you with your shopping, cooking or cleaning?

1-Yes

2-No

Comments: _____

4. Has she been going with you to medical appointments, giving you medications or helping you in any other way with your medical care?

BRSCR4

- 1-Yes
- 2-No

Comments: _____

5. Has your daughter been helping you deal with doctors, the hospital, your health insurance or providing you with any other help you might need because of your illness?

BRSCR5

- 1-Yes
- 2-No

Comments: _____

6. Has anyone else in your family provided you with help?

BRSCR6

- 1-Yes (Ask A)
- 2-No

A. Who helps? (Relationship to Patient)

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____

BRSCR6A1

BRSCR6A2

BRSCR6A3

BRSCR6A4

BRSCR6A5

7. **If Patient indicates that daughter helps in any way, ask:**
Overall, how many hours a week do you think your daughter spends helping you?

BRSCR7

_____ # of hours (IF LESS THAN 4 HOURS, ASK A)

- A. Since your diagnosis, was there a period when your daughter was spending more time helping you?

BRSCR7A

- 1-Yes (Ask B)
2-No

- B. During that time, about how many hours a week do you think she spent helping you?

BRSCR7B

_____ # of hours (IF LESS THAN 4 HOURS, ASK C)

- C. Do you think, in the future, your daughter will be spending more time with you?

BRSCR7C

- 1-Yes
2-No

PATIENT'S MEDICAL INFORMATION

The following questions refer to your breast cancer diagnosis and treatment.

1. To the best of your knowledge, what was the date of your cancer diagnosis?

BRMED1MO

____/____/____
mo da yr

BRMED1DA
BRMED1YR

2. To the best of your knowledge, what is the extent of your breast cancer? Is it...

BRMED2

1-Local

BRMED2RV1

2-Regional

BRMED2RV2

3-Metastatic

Organs Involved: _____

BRMED2RV3

3. Do you have a 2nd primary cancer?

BRMED3

1-Yes

Site: _____

BRMED3RV1

2-No

4. What type of treatment has been recommended by your physician for your cancer?

- a. Surgery:

BRMED4A

1-Yes

2-No

- b. Chemotherapy:

BRMED4B

1-Yes

2-No

- c. Radiation:

BRMED4C

1-Yes

2-No

- d. Other:

BRMED4D

1-Yes

2-No

Screeners#

9. Hx Comments:

BRMED9RV1
BRMED9RV2
BRMED9RV3

10. Tx Comments:

BRMED10RV1
BRMED10RV2
BRMED10RV3

11. Comments:

BRMED11RV1
BRMED11RV2
BRMED11RV3

12. Patient's Primary Caregiver: _____

BRMED12

DYAD ELIGIBILITY

1. Is this dyad eligible for the study?

BRELG1

1-Yes (Answer A)

2-No (Skip to C)

A. Did dyad complete T1 interview?

BRELG1A

1-Yes (Skip to 14)

2-No (Answer B, Skip C)

B. Why was T1 not completed?

BRELG1B

1-Daughter declined participation

2-Patient declined participation

3-Unable to contact to schedule T1

4-Patient died

5-Patient declined permission to contact daughter

6-Other ()

C. Why is dyad ineligible?

BRELG1C

1-No daughter

2-Ineligible due to extent of cancer

3-Daughter is not a caregiver

4-Received prior cancer diagnosis

5-Misdiagnosed, no cancer

6-Eligibility period expired

7-Patient refused to complete screening

8-Other ()

1. Date of Screening: / /
 mo da yr

BRELG2MO
BRELG2DA
BRELG2YR

3. Screened by: _____

BRELG3

4. Additional Comments:

BRELG4RV1
BRELG4RV2
BRELG4RV3

IF DAUGHTER PROVIDES 4 OR MORE HOURS OF HELP A WEEK OR PARENT FEELS DAUGHTER WILL BE HELPING MORE IN THE FUTURE ASK FOR DAUGHTER'S NAME, ADDRESS AND PHONE NUMBER.

Daughter's Name _____

Address _____

City, State & Zip _____

Phone Number _____

Best time to call _____

LOG OF PHONE CALLS AND CONTACTS

Record Results As:

1-no answer

3-phone disconnected

5-person not there

7-dtr called

2-busy

4-answering machine

6-person contacted

| | DATE | TIME | RESULTS |
|----|------|------|---------|
| 1. | | | |
| 2. | | | |
| 3. | | | |
| 4. | | | |
| 5. | | | |
| 6. | | | |
| 7. | | | |
| 8. | | | |

1. Did daughter agree to participate?

1-Yes

2-No (If No, Why?)

BRDTR1

WHY?

BRDTR1RV1

BRDTR1RV2

BRDTR1RV3

APPENDIX E

**Daughter Informed Consent Form
(English/Spanish)**

| | | | |
|--------------------------------------|-----------|-----------------|---------|
| Institutional Review Board (CPMCIRB) | | | |
| IRB # | 9585 | Approval Date | 5/2/01 |
| Initials | <u>SC</u> | Expiration Date | 3/28/02 |
| Columbia Presbyterian Medical Center | | | |

Columbia Presbyterian Medical Center -- Consent to Participate in a Research Study

ADULT DAUGHTER CONSENT FORM

The purpose of this consent form is to provide you with the information you need to consider in deciding whether to participate in this research study.

Study title: IRB #: 9585, "Aging families and breast cancer: Multigenerational Issues"

Study purpose:

You are invited to participate in a research study. The purpose of this study is to investigate the illness and treatment-related issues patients diagnosed with breast cancer and their care giving daughters are experiencing. You qualify as a possible participant in this study because you are providing care to your mother who has been diagnosed with breast cancer.

Study procedures:

If you decide to participate in this study we are asking you to participate in a two and one-half hour face-to-face research meeting with a research clinician. This research meeting will be scheduled at your convenience. It will be held at our research offices at 100 Haven Avenue, about three blocks away from the hospital. In the first part of the meeting you will be asked to answer a questionnaire that will take about 50-60 minutes to complete. The questionnaire will contain questions about your mother's illness, treatment experiences and needs for assistance. We will also ask you about your care giving and some background questions about yourself. You can choose not to answer any question. In the second part of the research meeting, we will ask you to tell us in greater detail about how your mother's illness and its treatment has impacted on your life. We will also ask you about other illness-related issues and concerns you may have. This portion of the research meeting will take about 90 minutes and with your permission (please indicate by checkmark below), we will tape record it so that it can be typed up and analyzed.

- ☐ Yes, I agree to the tape recording
☐ No, I do not agree to the tape recording

Study risks:

Your participation in this study involves the following risk: Talking with the research clinician may cause you to confront some sensitive feelings and issues related to your mother's breast cancer and its treatment. For this reason, the interviewer is an experienced clinician who has been trained to address any such distress. There are no physical risks anticipated to your participation in this study.

Please initial page: _____ Participant/ _____ Witness

Study benefits:

You may or may not benefit personally from this study. We have found that some patients and their families find the opportunity of talking with a research clinician about their experiences and concerns to be beneficial and you may also find this a benefit. Your participation may benefit society by contributing to our understanding of the illness and treatment-related issues patients diagnosed with breast cancer and their care giving daughters are experiencing.

Alternatives:

An alternative to study participation is to not participate in the study.

Costs:

There will be no costs to you for participating in this study. You will be paid back for any travel costs and child care costs you may have in coming to research meeting.

Compensation:

For your participation in this study you will receive \$30 to compensate you for your time and effort in participating in the study in addition to the money you are given for your travel and child care costs. The interviewer will give you the money at the end of the research meeting.

Confidentiality:

Any information obtained during this study and identified with you will remain confidential. Your name or other personally identifying information will not be used in any reports or publications from the study. Your comments about the program will be identified by a unique code number and kept in locked files in our research office. This study has been funded by the Department of Defense. Representatives from the U.S. Army Medical Research and Materiel Command are eligible to inspect the records of this research as part of their responsibilities to protect human subjects in research.

Participation is voluntary:

Your participation in this study is completely voluntary. You can refuse to participate or withdraw from the study at any time and such a decision will not affect your mother's medical care at New York Presbyterian Medical Center now or in the future. Signing this form does not waive any of your legal rights.

Questions:

If you have any questions, please ask, and we will do our best to answer them. If you have additional questions in the future, you can reach Dr. Victoria H. Raveis at (212) 304-5566. If you have any questions about your rights as a research subject, you can call the Institutional Review Board at (212) 305-5883 for information.

Please initial page: ____ Participant/ ____ Witness

Statement of consent:

I have discussed this study with _____ (Consenting Investigator) to my satisfaction. I understand that my participation is voluntary and that I can withdraw from the study at any time without prejudice. I have read the above and agree to enter this research study. Signing this form does not waive any of my legal rights.

I have been informed that if I believe that I have sustained injury as a result of participating in a research study, I may contact the Principal Investigator, Dr. Victoria H. Raveis at (212) 304-5569 or the Institutional Review Board, at 212-305-5883 so that I can review the matter and identify the medical resources which may be available to me.

I understand that I will receive a copy of this consent form.

Signatures:

| | | |
|-----------------------|---------------------|-----------------------|
| _____ | _____ | _____ |
| Participant signature | Name (Please print) | Date (Month/Day/Year) |

| | |
|--------------------------------|--------------|
| _____ | _____ |
| Participant's address (Street) | (City/State) |

| | | |
|--|---------------------|-----------------------|
| _____ | _____ | _____ |
| Signature of investigator obtaining consent | Name (Please print) | Date (Month/Day/Year) |

| | | |
|---|---------------------|-----------------------|
| _____ | _____ | _____ |
| Signature of witness to the informed consent | Name (Please print) | Date (Month/Day/Year) |

The solicitation of subjects into this study has been approved by the Columbia Presbyterian Medical Center Institutional Review Board.

IRB approval date: _____

Approval expiration date: _____

El Centro Médico de Columbia Presbyterian -- Consentimiento Para Participar en una Investigación

FORMULARIO DE CONSENTIMIENTO INFORMADO PARA LA HIJA ADULTA

El objetivo de este formulario de consentimiento es darle la información que necesita considerar para decidir si quiere participar en esta investigación.

Título de Estudio: IRB #: 9585, "Envejecimiento de familiares y cáncer del seno: problemas multigeneracionales"

PROPÓSITO

Se le está pidiendo que participe en una investigación. El objetivo de este estudio es investigar los problemas relacionados con la enfermedad y el tratamiento de las pacientes diagnosticadas con cáncer del seno y la experiencia de sus hijas que las atienden. Usted califica como posible participante en este estudio porque usted está cuidando a su madre que ha sido diagnosticada con cáncer del seno.

DESCRIPCIÓN DEL ESTUDIO

Si usted está de acuerdo en participar, le solicitaremos que participe en una entrevista frente a frente con un clínico de la investigación. Esta entrevista dura dos horas y media. La entrevista se realizará a una hora que le sea conveniente a usted y se llevará a cabo en nuestras oficinas localizadas en 100 Avenida Haven, casi a tres cuadras del hospital. En la primera parte de la entrevista, le pediremos que conteste un cuestionario que le tomará como 50-60 minutos. Este cuestionario tiene preguntas sobre la enfermedad de su madre, las experiencias del tratamiento y la necesidad de ayuda. También se le harán preguntas con respecto al cuidado que usted le brinda a su madre, y algunas preguntas sobre su propio historial. Usted tendrá la opción de rehusar a contestar cualquier pregunta. En la otra parte de la entrevista, le pediremos que nos diga con más detalle cómo la enfermedad y el tratamiento de su madre le han impactado. También se le harán preguntas sobre otros problemas relacionados con la enfermedad y las preocupaciones que pueda tener usted. Esta parte de la entrevista tomará 90 minutos y con su permiso (indique su decisión con una marca a continuación), grabaremos la entrevista para poder escribirla a máquina y analizar su información.

_____ Si, estoy de acuerdo en grabar una cinta
_____ No, yo no estoy de acuerdo en grabar una cinta

RIESGOS DEL ESTUDIO

Su participación en este estudio incluye los riesgos siguientes: el hablar con un clínico de la investigación puede hacer que usted tenga algunas emociones relacionadas con problemas y sentimientos acerca de la enfermedad y el tratamiento de su madre. Por esta razón, la persona encargada de conducir la entrevista es un clínico con experiencia que ha recibido entrenamiento para

manejar cualquier sentimiento de angustia. No hay riesgos físicos previstos por su participación.

BENEFICIOS DEL ESTUDIO

Usted puede beneficiarse personalmente del estudio o no. Hemos encontrado que algunas pacientes y sus familiares se benefician al tener la oportunidad de hablar con el clínico de la investigación y usted también puede beneficiarse. Su participación puede beneficiar a la sociedad, ya que contribuirá al entendimiento de los problemas relacionados con el tratamiento y la enfermedad de las pacientes con cáncer del seno y de la experiencia de sus hijas que las cuidan.

ALTERNATIVAS

Una alternativa a la participación en el estudio es no participar.

COSTOS

No habrá ningún costo para usted por participar en el estudio. Se le reembolsará todo el costo del viaje y del cuidado de sus niños que pueda tener por venir a la entrevista.

COMPENSACIÓN

Para compensar su tiempo y esfuerzo por participar en este estudio, recibirá treinta dólares. Este dinero es además del dinero que usted va a recibir por su viaje y el cuidado de sus niños. El entrevistador le dará su dinero al terminar la entrevista.

CONFIDENCIALIDAD

Toda información obtenida durante el estudio y que la identifique a usted se mantendrá confidencial. Su nombre o cualquier información que la identifique personalmente no se utilizará ni en informes ni publicaciones de este estudio. Todos sus comentarios sobre el programa serán identificados con números de código, y serán archivados, bajo llave, en nuestras oficinas. El Departamento de Defensa proporcionó los fondos para este estudio. Los representantes del Army Medical Research and Materiel Command de los Estados Unidos son elegibles para revisar los expedientes de esta investigación como parte de sus responsabilidades para proteger a los sujetos de una investigación.

SU PARTICIPACIÓN ES VOLUNTARIA

Su participación en esta investigación es completamente voluntaria. Usted puede negarse a participar o retirarse en cualquier momento, y su decisión no afectará el cuidado médico de su madre en el Centro Médico de New York Presbyterian ni ahora ni en el futuro. Al firmar este formulario no renuncia a ninguno de sus derechos legales.

PREGUNTAS

Si tiene preguntas, por favor hágalas y haremos todo lo posible por contestarlas. Si tiene preguntas adicionales en el futuro, puede llamar a la Dra. Victoria H. Raveis. Su número telefónico es el (212)

304-5566. Si tiene preguntas sobre su derechos como sujeto de estudio, podrá llamar a la Comisión Institucional de Revisión a (212) 305-5883 para más información.

DECLARACIÓN DEL PARTICIPANTE

Yo he discutido el estudio a fondo con _____ (Investigador/a que solicita el consentimiento) para mi satisfacción. Comprendo que mi participación en este estudio es voluntaria y que puedo retirarme en cualquier momento sin penalidad. He leído todo lo anterior y estoy de acuerdo en participar en esta investigación. Al firmar este formulario no renuncio a mis derechos legales.

Me han informado que si creo que he sufrido una lesión como resultado de mi participación en esta investigación, puedo comunicarme con la Investigadora Principal, Dra. Victoria H. Raveis en el (212) 304-5566 o con la Comisión Institucional de Revisión a (212) 305-5883 para poder revisar la materia e identificar los recursos médicos disponibles para mí.

Entiendo que voy a recibir una copia de este formulario.

Firmas:

| | | |
|---------------------------------|-------------------------------------|------------------------------|
| _____ Firma del Participante | _____ Nombre (en letra de molde) | _____ Fecha (Mes/Día/Año) |
|---------------------------------|-------------------------------------|------------------------------|

| | |
|---|--------------------------|
| _____ Dirección del Participante (calle) | _____ (Ciudad/Estado) |
|---|--------------------------|

| | | |
|--|-------------------------------------|------------------------------|
| _____ Firma de la Investigadora obteniendo el consentimiento | _____ Nombre (en letra de molde) | _____ Fecha (Mes/Día/Año) |
|--|-------------------------------------|------------------------------|

| | | |
|--|-------------------------------------|------------------------------|
| _____ Firma del Testigo del consentimiento informado | _____ Nombre (en letra de molde) | _____ Fecha (Mes/Día/Año) |
|--|-------------------------------------|------------------------------|

La solicitud de personas para este estudio ha sido aprobado por La Comisión Institucional de Revisión del Centro Médico de Columbia Presbyterian.

Reviewed by: 46 06-07-01

The Hispanic Research and Recruitment Center
Columbia-Presbyterian Medical Center

Por favor ponga sus iniciales en la página: _____ Participante/ _____ Testigo

APPENDIX F

Patient Questionnaire (English/Spanish)

CODED _____

ENTERED _____

VERIFIED _____

Time Started
_____ am/pm

Time Ended
_____ am/pm

**Aging Families and Breast Cancer:
Multigenerational Issues**

Patient Interview

ID# _____

TIME BEGUN:

____ / ____ a.m./p.m.

SOCIODEMOGRAPHIC QUESTIONS

1. What is your date of birth?

____ / ____ / ____
month day year

BRPS1MO
BRPS1DA
BRPS1YR

2. What is the highest level of schooling you have completed?

Eighth grade or less1
Some High School.....2
High School Graduate or GED.....3
Some College4
Associate's Degree.....5
Technical or vocational school.....6
College Degree.....7
Some graduate school.....8
Graduate or professional degree9

BRPS2

3. How would you describe yourself? Would you say you are...

White1 (ASK A)
Black/African American.....2 (ASK A)
Asian or Pacific Islander3
American Indian/Alaskan native4
Other (SPECIFY _____)5 (ASK A)

BRPS3

- A. Are you of Hispanic origin or descent?

Yes.....1 (ASK B)
No2

BRPS3A

- B. Do you consider yourself to be...

Puerto Rican1
Dominican2
Cuban3
Mexican4
Ecuadorean5
Columbian6
Spanish or European.....7
Something else (SPECIFY: _____)10

BRPS3B

4. Are you currently employed, not employed, on disability, out on sick leave, or something else?

BRPS4

- Employed1 (ASK A)
Disability2 (ASK C)
Sick Leave3 (ASK C)
Not employed, laid off, looking for work4 (ASK B)
Retired5 (ASK C)
In school and not working6 (ASK B)
Keeping house7 (ASK B)
Other (SPECIFY _____).....8 (ASK B)

A. (IF EMPLOYED) About how many hours do you work in an average week?

BRPS4A

_____ # of hours IF LESSTHAN 35 HOURS GO TO D.
IF 35+ GO TO Q.5.

B. Have you ever held a job which lasted for six months or longer?

BRPS4B

Yes..... 1
No..... 2 (IF NO, GO TO Q. 8)

C. In what month and year did you last work?

BRPS4CMO
BRPS4CYR

_____/_____
month year

D. (IF WORKING PART-TIME OR NOT WORKING) Are you (working part-time/
not working) because of your illness?

BRPS4D

Yes..... 1
No..... 2

5. What kind of work (do)(did) you do? That is, what (is)(was) your job called? (PROBE, IF
NECESSARY) What (do)(did) you actually do in that job? What (are) were some of your main duties
or responsibilities?

BRPS5

Occupation: _____

Job Title: _____

Duties: _____

A. What kind of company or industry is that? What do/did they do or make at the place where
you work(ed)?

BRPS5A

6. Are/Were you self employed in your own business, practice, or working without pay in a family
business (on your main job)?

BRPS6

Yes, self employed 1
No, work for someone else 2

7. (What is/When you were working, what was) your annual salary before taxes from your job?
I'll start reading off a list of income ranges; just stop me when I reach the category that includes
your income.

BRPS7

| | | |
|---------------------------|----|---------|
| \$5,000 or less..... | 1 | |
| \$5,001 - \$10,000..... | 2 | |
| \$10,001 - \$15,000..... | 3 | |
| \$15,001 - \$20,000..... | 4 | |
| \$20,001 - \$25,000..... | 5 | |
| \$25,001 - \$30,000..... | 6 | |
| \$30,001 - \$40,000..... | 7 | |
| \$40,001 - \$50,000..... | 8 | |
| \$50,001 - \$60,000..... | 9 | |
| \$60,001 - \$70,000..... | 10 | |
| \$70,001 - \$80,000..... | 11 | |
| \$80,001 - \$90,000..... | 12 | |
| \$90,001 - \$100,000..... | 13 | |
| \$100,001 or more | 14 | |
| Does not know..... | 97 | (ASK A) |
| Refuses to answer | 99 | (ASK A) |

- A. Can you tell me if it was...

BRPS7A

| | |
|------------------------------------|---|
| Less than \$25,000 a year or | 1 |
| More than \$25,000 a year | 2 |
| DOESN'T KNOW; REFUSED | 3 |

8. What is your current marital status?

BRPS8

| | | |
|---|---|---------|
| Married..... | 1 | (ASK A) |
| IF VOLUNTEERED: Living with a partner | 2 | (ASK A) |
| Divorced | 3 | |
| Separated | 4 | |
| Widowed | 5 | |
| Never Married | 6 | |

- A. How long have you been (married/living together)?

BRPS8A

number of years

9. How many children do you have?

BRPS9

number of children

10. Could you please tell me who lives with you in your household? **IF R. LIVES ALONE GO TO Q. 11. (ASK A-C FOR EACH PERSON IN HOUSEHOLD) (NOTE: IF HOUSEHOLD COMPOSITION HAS CHANGED FROM THE USUAL, CODE FOR COMPOSITION IN THE LAST MONTH), PROBE:** Anyone else?

| A. What is their relationship to you? | B. Sex Male Female | C. What was his/her age on his/her last birthday? |
|--|----------------------------|--|
| Pers. 1. _____ | 1 2 | _____ |
| Pers. 2. _____ | 1 2 | _____ |
| Pers. 3. _____ | 1 2 | _____ |
| Pers. 4. _____ | 1 2 | _____ |
| Pers. 5. _____ | 1 2 | _____ |
| Pers. 6. _____ | 1 2 | _____ |
| Pers. 7. _____ | 1 2 | _____ |
| Pers. 8. _____ | 1 2 | _____ |

BRPS10R1
BRPS10S1
BRPS10A1

BRPS10R2
BRPS10S2
BRPS10A2

BRPS10R3
BRPS10S3
BRPS10A3

BRPS10R4
BRPS10S4
BRPS10A4

BRPS10R5
BRPS10S5
BRPS10A5

BRPS10R6
BRPS10S6
BRPS10A6

BRPS10R7
BRPS10S7
BRPS10A7

BRPS10R8
BRPS10S8
BRPS10A8

11. So, *including yourself*, the total number of people living in your household is: _____

BRPS11

NETWORK OF RELATIONSHIPS (Abbreviated)

We are interested in how illness changes relationships. In this next series of items we ask about how your relationship with your daughter has been *since your diagnosis* and how it was *prior to your illness*

| | | <u>Not at all or a little</u> | <u>Somewhat</u> | <u>Very</u> | <u>Extremely</u> | <u>The most</u> | <u>DNA</u> | |
|----|--|-----------------------------------|-----------------|-------------|------------------|---------------------|------------|---------|
| 1. | How much do you and your daughter get upset or mad at each other? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR1A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR1B |
| 2. | How satisfied are you with your relationship with your daughter? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR2A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR2B |
| 3. | How much do you tell your daughter everything? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR3A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR3B |
| 4. | How much do you help your daughter with things she can't do by herself? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR4A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR4B |
| 5. | How much does your daughter treat you like you're admired and respected? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR5A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR5B |
| 6. | How much do you and your daughter disagree and quarrel? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR6A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR6B |

| | | <u>Not at all or a little</u> | <u>Somewhat</u> | <u>Very</u> | <u>Extremely</u> | <u>The most</u> | <u>DNA</u> | |
|-----|--|-----------------------------------|-----------------|-------------|------------------|---------------------|------------|----------|
| 7. | How happy are you with the way things are between you and your daughter? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR7A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR7B |
| 8. | How much do you share your secrets and private feelings with your daughter? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR8A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR8B |
| 9. | How much do you protect and look out for your daughter? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR9A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR9B |
| 10. | How much does your daughter treat you like you're good at many things? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR10A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR10B |
| 11. | How much do you and your daughter argue with each other? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR11A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR11B |
| 12. | How good is your relationship with your daughter? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR12A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR12B |
| 13. | How much do you talk to your daughter about things that you don't want others to know? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR13A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR13B |

| | | <u>Not at all or a little</u> | <u>Somewhat</u> | <u>Very</u> | <u>Extremely</u> | <u>The most</u> | <u>DNA</u> | |
|-----|---|--|--------------------------------|---------------------------|-----------------------|-----------------------------------|------------|----------|
| 4. | How much do you take care of your daughter? | | | | | | | |
| a. | since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR14A |
| b. | prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR14B |
| 15. | How much does your daughter like or approve of the things you do? | | | | | | | |
| a. | since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR15A |
| b. | prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR15B |
| 16. | How close is your relationship with your daughter? | | | | | | | |
| a. | since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR16A |
| b. | prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR16B |
| | | <u>Daughter almost always does</u> | <u>Daughter often does</u> | <u>About the same</u> | <u>I often do</u> | <u>I almost always do</u> | <u>DNA</u> | |
| 17. | Who tells the other person what to do more often, you or your daughter? | | | | | | | |
| a. | since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR17A |
| b. | prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR17B |
| 18. | Between you and your daughter who tends to be the BOSS in this relationship? | | | | | | | |
| a. | since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR18A |
| b. | prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR18B |
| 19. | In your relationship with your daughter who tends to take charge and decide what should be done? | | | | | | | |
| a. | since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR19A |
| b. | prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR19B |

FILIAL OBLIGATION

In this next series of questions, we will be asking you your opinions about help in the home

1. Married children should live close to parents to provide care. Do you . .

Strongly agree 5
Somewhat agree 4
Neither agree nor disagree 3
Somewhat disagree 2
Strongly disagree 1

BRPFO1

2. Children should not be expected to do tasks for their parents. . .

Strongly agree 5
Somewhat agree 4
Neither agree nor disagree 3
Somewhat disagree 2
Strongly disagree 1

BRPFO2

3. Parents should expect adult children to assist them. . .

Strongly agree 5
Somewhat agree 4
Neither agree nor disagree 3
Somewhat disagree 2
Strongly disagree 1

BRPFO3

4. It is a child's duty to assist parents. . .

Strongly agree 5
Somewhat agree 4
Neither agree nor disagree 3
Somewhat disagree 2
Strongly disagree 1

BRPFO4

5. It is preferable to pay a professional for assistance with caregiving. . .

Strongly agree 5
Somewhat agree 4
Neither agree nor disagree 3
Somewhat disagree 2
Strongly disagree 1

BRPFO5

6. Paying for professional help means a relative is not taking responsibility. . .

Strongly agree 5
Somewhat agree 4
Neither agree nor disagree 3
Somewhat disagree 2
Strongly disagree 1

BRPFO6

7. It is better to give up a job to provide care than to pay a professional. . .

Strongly agree 5
Somewhat agree 4
Neither agree nor disagree 3
Somewhat disagree 2
Strongly disagree 1

BRPFO7

DAILY LIVING ACTIVITIES

As a result of illness, people often find that they have to change their routines. For each of the activities I am going to read to you, please tell me if you do it yourself, or you get some help with it, or whether someone did it for you even before your illness (**PROBE WHEN NECESSARY TO DETERMINE THAT HELP IS ILLNESS-RELATED**).

1. Who does your light housekeeping such as dusting, washing dishes and making beds? Do you do it yourself, get some help with it, or does someone do it for you?

BRPDL1

| | | |
|--|---|-------------|
| Does it alone | 1 | (ASK B) |
| Has help in doing this activity..... | 2 | (ASK A & B) |
| Someone is doing this activity for patient due to illness..... | 3 | (ASK A & B) |
| Other has always done it (not illness-related)..... | 4 | (ASK A) |
| Not done | 5 | (ASK B) |

- A. Who helps? (**CIRCLE ALL THAT APPLY**)

BRPDL1A

| | |
|-----------------------------------|----|
| Spouse..... | 1 |
| Caregiver Daughter | 2 |
| Other Daughter | 3 |
| Son | 4 |
| Daughter-in-law | 5 |
| Son-in-law | 6 |
| Brother..... | 7 |
| Sister..... | 8 |
| Other relative (WHO: _____) | 9 |
| Friend | 10 |
| Nurse, health aide..... | 11 |
| Co-worker/employee..... | 12 |
| Therapist..... | 13 |
| Social Worker..... | 14 |
| Doctor/Psychiatrist..... | 15 |
| Other (WHO: _____)..... | 16 |

- B. Do you need (more) help? (**IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?**)

BRPDL1B

| | |
|-----------|---|
| Yes | 1 |
| No..... | 2 |

2. Who does your heavy housekeeping such as mopping, vacuuming, laundry or cleaning the bathroom? Do you do it yourself, do you get some help with it, or does someone do it for you?

BRPDL2

| | | |
|--|---|-------------|
| Does it alone | 1 | (ASK B) |
| Has help in doing this activity..... | 2 | (ASK A & B) |
| Someone is doing this activity for patient due to illness..... | 3 | (ASK A & B) |
| Other has always done it (not illness-related)..... | 4 | (ASK A) |
| Not done | 5 | (ASK B) |

BRPDL2A

A. Who helps? (CIRCLE ALL THAT APPLY)

| | |
|-----------------------------------|----|
| Spouse..... | 1 |
| Caregiver Daughter | 2 |
| Other Daughter | 3 |
| Son | 4 |
| Daughter-in-law | 5 |
| Son-in-law | 6 |
| Brother..... | 7 |
| Sister..... | 8 |
| Other relative (WHO: _____) | 9 |
| Friend | 10 |
| Nurse, health aide..... | 11 |
| Co-worker/employee..... | 12 |
| Therapist..... | 13 |
| Social Worker..... | 14 |
| Doctor/Psychiatrist | 15 |
| Other (WHO: _____) | 16 |

BRPDL2B

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

| | |
|----------|---|
| Yes..... | 1 |
| No..... | 2 |

BRPDL3

3. Who does your cooking and meal preparation? Do you do it yourself, do you get some help with it, or does someone do it for you?

| | | |
|--|---|-------------|
| Does it alone | 1 | (ASK B) |
| Has help in doing this activity..... | 2 | (ASK A & B) |
| Someone is doing this activity for patient due to illness..... | 3 | (ASK A & B) |
| Other has always done it (not illness-related) | 4 | (ASK A) |
| Not done..... | 5 | (ASK B) |

BRPDL3A

A. Who helps? (CIRCLE ALL THAT APPLY)

| | |
|-----------------------------------|----|
| Spouse..... | 1 |
| Caregiver Daughter | 2 |
| Other Daughter | 3 |
| Son | 4 |
| Daughter-in-law | 5 |
| Son-in-law | 6 |
| Brother..... | 7 |
| Sister..... | 8 |
| Other relative (WHO: _____) | 9 |
| Friend | 10 |
| Nurse, health aide..... | 11 |
| Co-worker/employee..... | 12 |
| Therapist..... | 13 |
| Social Worker..... | 14 |
| Doctor/Psychiatrist | 15 |
| Other (WHO: _____) | 16 |

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPDL3B

Yes.....1
No.....2

4. Who does your shopping for clothes and household items? Do you do it yourself, do you get some help with it, or does someone do it for you?

BRPDL4

Does it alone1 (ASK B)
Has help in doing this activity.....2 (ASK A & B)
Someone is doing this activity for patient due to illness.....3 (ASK A & B)
Other has always done it (not illness-related).....4 (ASK A)
Not done5 (ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

BRPDL4A

Spouse.....1
Caregiver Daughter.....2
Other Daughter.....3
Son.....4
Daughter-in-law.....5
Son-in-law.....6
Brother.....7
Sister.....8
Other relative (WHO:.....).....9
Friend.....10
Nurse, health aide.....11
Co-worker/employee.....12
Therapist.....13
Social Worker.....14
Doctor/Psychiatrist.....15
Other (WHO:.....).....16

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPDL4B

Yes.....1
No.....2

5. Who does your grocery shopping? Do you do it yourself, do you get some help with it, or does someone do it for you?

BRPDL5

Does it alone1 (ASK B)
Has help in doing this activity.....2 (ASK A & B)
Someone is doing this activity for patient due to illness.....3 (ASK A & B)
Other has always done it (not illness-related).....4 (ASK A)
Not done5 (ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

BRPDL5A

- Spouse.....1
- Caregiver Daughter2
- Other Daughter.....3
- Son4
- Daughter-in-law5
- Son-in-law6
- Brother.....7
- Sister.....8
- Other relative (WHO: _____).....9
- Friend10
- Nurse, health aide.....11
- Co-worker/employee.....12
- Therapist.....13
- Social Worker.....14
- Doctor/Psychiatrist15
- Other (WHO: _____).....16

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPDL5B

- Yes.....1
- No2

6. Do you bathe and shower by yourself or does someone help you?

BRPDL6

- Does it alone1 (ASK B)
- Has help in doing this activity.....2 (ASK A & B)
- Someone is doing this activity for patient due to illness.....3 (ASK A & B)
- Other has always done it (not illness-related).....4 (ASK A)
- Not done5 (ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

BRPDL6A

- Spouse.....1
- Caregiver Daughter2
- Other Daughter.....3
- Son4
- Daughter-in-law5
- Son-in-law6
- Brother.....7
- Sister.....8
- Other relative (WHO: _____).....9
- Friend10
- Nurse, health aide.....11
- Co-worker/employee.....12
- Therapist.....13
- Social Worker.....14
- Doctor/Psychiatrist15
- Other (WHO: _____).....16

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPDL6B

Yes1
No2

7. Do you perform any home health care tasks, such as keeping track of medications or changing your dressings by yourself, do you get some help with this, or does someone do it for you?

BRPDL7

Does it alone1 (ASK B)
Has help in doing this activity.....2 (ASK A & B)
Someone is doing this activity for patient due to illness.....3 (ASK A & B)
Other has always done it (not illness-related).....4 (ASK A)
Not done.....5 (ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

BRPDL7A

Spouse.....1
Caregiver Daughter.....2
Other Daughter.....3
Son.....4
Daughter-in-law.....5
Son-in-law.....6
Brother.....7
Sister.....8
Other relative (WHO: _____).....9
Friend.....10
Nurse, health aide.....11
Co-worker/employee.....12
Therapist.....13
Social Worker.....14
Doctor/Psychiatrist.....15
Other (WHO: _____).....16

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPDL7B

Yes1
No2

8. Do you get dressed by yourself, or does someone help you?

BRPDL8

Does it alone1 (ASK B)
Has help in doing this activity.....2 (ASK A & B)
Someone is doing this activity for patient due to illness.....3 (ASK A & B)
Other has always done it (not illness-related).....4 (ASK A)
Not done.....5 (ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

BRPDL8A

- Spouse.....1
- Caregiver Daughter2
- Other Daughter3
- Son4
- Daughter-in-law5
- Son-in-law6
- Brother.....7
- Sister.....8
- Other relative (WHO: _____).....9
- Friend10
- Nurse, health aide.....11
- Co-worker/employee.....12
- Therapist.....13
- Social Worker.....14
- Doctor/Psychiatrist.....15
- Other (WHO: _____).....16

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPDL8B

- Yes.....1
- No.....2

9. Are you able to use the toilet by yourself, or does someone help you?

BRPDL9

- Does it alone1 (ASK B)
- Has help in doing this activity.....2 (ASK A & B)
- Someone is doing this activity for patient due to illness.....3 (ASK A & B)
- Other has always done it (not illness-related).....4 (ASK A)
- Not done.....5 (ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

BRPDL9A

- Spouse.....1
- Caregiver Daughter2
- Other Daughter3
- Son4
- Daughter-in-law5
- Son-in-law6
- Brother.....7
- Sister.....8
- Other relative (WHO: _____).....9
- Friend10
- Nurse, health aide.....11
- Co-worker/employee.....12
- Therapist.....13
- Social Worker.....14
- Doctor/Psychiatrist.....15
- Other (WHO: _____).....16

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPDL9B

Yes1
No2

10. Do you get in and out of a bed or chair by yourself, or does someone help you?

BRPDL10

Does it alone1 (ASK B)
Has help in doing this activity.....2 (ASK A & B)
Someone is doing this activity for patient due to illness.....3 (ASK A & B)
Other has always done it (not illness-related).....4 (ASK A)
Not done.....5 (ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

BRPDL10A

Spouse.....1
Caregiver Daughter2
Other Daughter3
Son4
Daughter-in-law5
Son-in-law6
Brother.....7
Sister.....8
Other relative (WHO: _____).....9
Friend10
Nurse, health aide.....11
Co-worker/employee.....12
Therapist.....13
Social Worker.....14
Doctor/Psychiatrist15
Other (WHO: _____).....16

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPDL10B

Yes1
No2

11. When you travel to your medical appointments at the hospital, do you usually go by yourself or does someone go with you?

BRPDL11

Does it alone1 (ASK B)
Has help in doing this activity.....2 (ASK A & B)
Someone is doing this activity for patient due to illness.....3 (ASK A & B)
Other has always done it (not illness-related).....4 (ASK A)
Not done.....5 (ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

BRPDL11A

- Spouse.....1
- Caregiver Daughter2
- Other Daughter3
- Son4
- Daughter-in-law5
- Son-in-law6
- Brother.....7
- Sister.....8
- Other relative (WHO: _____).....9
- Friend10
- Nurse, health aide.....11
- Co-worker/employee.....12
- Therapist.....13
- Social Worker.....14
- Doctor/Psychiatrist.....15
- Other (WHO: _____).....16

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPDL11B

- Yes.....1
- No.....2

12. When you travel for other purposes such as work, visiting, or errands, do you usually go by yourself or does someone go with you?

BRPDL12

- Does it alone1 (ASK B)
- Has help in doing this activity.....2 (ASK A & B)
- Someone is doing this activity for patient due to illness.....3 (ASK A & B)
- Other has always done it (not illness-related).....4 (ASK A)
- Not done.....5 (ASK B)

A. Who helps? (CIRCLE ALL THAT APPLY)

BRPDL12A

- Spouse.....1
- Caregiver Daughter2
- Other Daughter3
- Son4
- Daughter-in-law5
- Son-in-law6
- Brother.....7
- Sister.....8
- Other relative (WHO: _____).....9
- Friend10
- Nurse, health aide.....11
- Co-worker/employee.....12
- Therapist.....13
- Social Worker.....14
- Doctor/Psychiatrist.....15
- Other (WHO: _____).....16

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPDL12B

- Yes.....1
- No.....2

13. Do you fill out forms such as insurance claims, medical forms, and applications for financial benefits yourself, do you get some help with it or does someone do it for you?

BRPDL13

- | | | |
|--|---|-------------|
| Does it alone | 1 | (ASK B) |
| Has help in doing this activity..... | 2 | (ASK A & B) |
| Someone is doing this activity for patient due to illness..... | 3 | (ASK A & B) |
| Other has always done it (not illness-related)..... | 4 | (ASK A) |
| Not done..... | 5 | (ASK B) |

A. Who helps? (CIRCLE ALL THAT APPLY)

BRPDL13A

- | | |
|-----------------------------------|----|
| Spouse..... | 1 |
| Caregiver Daughter | 2 |
| Other Daughter | 3 |
| Son | 4 |
| Daughter-in-law | 5 |
| Son-in-law | 6 |
| Brother..... | 7 |
| Sister..... | 8 |
| Other relative (WHO: _____) | 9 |
| Friend | 10 |
| Nurse, health aide..... | 11 |
| Co-worker/employee..... | 12 |
| Therapist..... | 13 |
| Social Worker..... | 14 |
| Doctor/Psychiatrist | 15 |
| Other (WHO: _____) | 16 |

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPDL13B

- | | |
|----------|---|
| Yes..... | 1 |
| No..... | 2 |

14. Do you handle your banking by yourself; that is, make deposits and withdrawals, pay bills, write checks, maintain a checking account, or do you get some help with it, or does someone do it for you?

BRPDL14

- | | | |
|--|---|-------------|
| Does it alone | 1 | (ASK B) |
| Has help in doing this activity..... | 2 | (ASK A & B) |
| Someone is doing this activity for patient due to illness..... | 3 | (ASK A & B) |
| Other has always done it (not illness-related)..... | 4 | (ASK A) |
| Not done..... | 5 | (ASK B) |

A. Who helps? (CIRCLE ALL THAT APPLY)

BRPDL14A

| | |
|----------------------------|----|
| Spouse..... | 1 |
| Caregiver Daughter | 2 |
| Other Daughter | 3 |
| Son | 4 |
| Daughter-in-law | 5 |
| Son-in-law | 6 |
| Brother..... | 7 |
| Sister..... | 8 |
| Other relative (WHO:.....) | 9 |
| Friend | 10 |
| Nurse, health aide..... | 11 |
| Co-worker/employee..... | 12 |
| Therapist..... | 13 |
| Social Worker..... | 14 |
| Doctor/Psychiatrist | 15 |
| Other (WHO:.....) | 16 |

B. Do you need (more) help? (IF NOT DONE, ASK: IF IT WERE DONE, WOULD YOU NEED ANY HELP?)

BRPDL14B

| | |
|-----------|---|
| Yes | 1 |
| No | 2 |

15. Do you need help or are you getting help in obtaining information about your illness or treatment?

BRPDL15

| | |
|--------------------------------------|---|
| Has no need | 1 |
| Has help in doing this activity..... | 2 |
| Needs help | 3 |

(ASK A & B)

A. Who helps? (CIRCLE ALL THAT APPLY)

BRPDL15A

| | |
|----------------------------|----|
| Spouse..... | 1 |
| Caregiver Daughter | 2 |
| Other Daughter | 3 |
| Son | 4 |
| Daughter-in-law | 5 |
| Son-in-law | 6 |
| Brother..... | 7 |
| Sister..... | 8 |
| Other relative (WHO:.....) | 9 |
| Friend | 10 |
| Nurse, health aide..... | 11 |
| Co-worker/employee..... | 12 |
| Therapist..... | 13 |
| Social Worker..... | 14 |
| Doctor/Psychiatrist | 15 |
| Other (WHO:.....) | 16 |

B. Do you need (more) help?

BRPDL15B

| | |
|-----------|---|
| Yes | 1 |
| No | 2 |

16. Do you need or are you getting illness-related financial counseling or advice?

BRPDL16

- Has no need1
 Getting counseling2
 Needs counseling3

(ASK A & B)

A. Who helps? (CIRCLE ALL THAT APPLY)

BRPDL16A

- Spouse.....1
 Caregiver Daughter2
 Other Daughter3
 Son4
 Daughter-in-law5
 Son-in-law6
 Brother.....7
 Sister.....8
 Other relative (WHO: _____).....9
 Friend10
 Nurse, health aide.....11
 Co-worker/employee.....12
 Therapist.....13
 Social Worker.....14
 Doctor/Psychiatrist.....15
 Other (WHO: _____).....16

B. Do you need (more) help?

BRPDL16B

- Yes.....1
 No.....2

17. Do you need or are you getting illness-related legal counseling or advice such as power of attorney?

BRPDL17

- Has no need1
 Getting counseling2
 Needs counseling3

(ASK A & B)

A. Who helps? (CIRCLE ALL THAT APPLY)

BRPDL17A

- Spouse.....1
 Caregiver Daughter2
 Other Daughter3
 Son4
 Daughter-in-law5
 Son-in-law6
 Brother.....7
 Sister.....8
 Other relative (WHO: _____).....9
 Friend10
 Nurse, health aide.....11
 Co-worker/employee.....12
 Therapist.....13
 Social Worker.....14
 Doctor/Psychiatrist.....15
 Other (WHO: _____).....16

B. Do you need (more) help?

BRPDL17B

- Yes.....1
 No.....2

ILLNESS PREDICTABILITY

- | | | | |
|----|--|---|--------|
| 1. | I usually know when I am going to have a good or bad day. Do you . . | | BRPIP1 |
| | Strongly agree | 5 | |
| | Somewhat agree | 4 | |
| | Neither agree nor disagree | 3 | |
| | Somewhat disagree | 2 | |
| | Strongly disagree | 1 | |
| 2. | It is clear to me when my illness is getting better or worse. Do you . . | | BRPIP2 |
| | Strongly agree | 5 | |
| | Somewhat agree | 4 | |
| | Neither agree nor disagree | 3 | |
| | Somewhat disagree | 2 | |
| | Strongly disagree | 1 | |
| 3. | I can generally predict the course of my illness. Do you . . | | BRPIP3 |
| | Strongly agree | 5 | |
| | Somewhat agree | 4 | |
| | Neither agree nor disagree | 3 | |
| | Somewhat disagree | 2 | |
| | Strongly disagree | 1 | |
| 4. | My physical distress is predictable. Do you . . | | BRPIP4 |
| | Strongly agree | 5 | |
| | Somewhat agree | 4 | |
| | Neither agree nor disagree | 3 | |
| | Somewhat disagree | 2 | |
| | Strongly disagree | 1 | |

ILLNESS CONTROL

- | | | | |
|----|--|---|--------|
| 5. | How much personal control do you think you have over the amount of fatigue you experience from day to day? Would you say you have . . | | BRPIC5 |
| | No control | 5 | |
| | Very little control | 4 | |
| | A moderate amount of control | 3 | |
| | Quite a bit of control | 2 | |
| | An extreme amount of control | 1 | |
| | DOES NOT APPLY | 8 | |
| 6. | How much personal control do you think you have over the amount of discomfort you experience from day to day? Would you say you have . . | | BRPIC6 |
| | No control | 5 | |
| | Very little control | 4 | |
| | A moderate amount of control | 3 | |
| | Quite a bit of control | 2 | |
| | An extreme amount of control | 1 | |
| | DOES NOT APPLY | 8 | |

7. How much personal control do you think you have over the amount of immobility you experience from day to day? Would you say you have. . .

BRPIC7

No control 5
Very little control 4
A moderate amount of control 3
Quite a bit of control 2
An extreme amount of control 1
DOES NOT APPLY 8

8. How much personal control do you think you have over the amount of pain you experience from day to day? Would you say you have. . .

BRPIC8

No control 5
Very little control 4
A moderate amount of control 3
Quite a bit of control 2
An extreme amount of control 1
DOES NOT APPLY 8

9. How much personal control do you believe you have over the long-term course of your illness, (that is, whether it will improve or at least not worsen in the future)? Would you say you have. . .

BRPIC9

No control 5
Very little control 4
A moderate amount of control 3
Quite a bit of control 2
An extreme amount of control 1
DOES NOT APPLY 8

10. How much personal control do you think you have over the medical care and treatment of your illness? Would you say you have. . .

BRPIC10

No control 5
Very little control 4
A moderate amount of control 3
Quite a bit of control 2
An extreme amount of control 1
DOES NOT APPLY 8

CES-D SCALE

I will now read you a list of the ways you might have felt or behaved *during the past week*. As I read each statement, please tell me the category which best describes how often you have felt this way *during the past week*.

| | Rarely Or None Of The Time (Less Than <u>1 Day</u>) | Some Or A Little of The Time (<u>1-2 Days</u>) | Occasionally Or A Moderate Amount of Time (<u>3-4 Days</u>) | Most Or All Of The Time (<u>5-7 Days</u>) | |
|---|--|---|--|--|----------|
| <i>During the past week:</i> | | | | | |
| 1. I was bothered by things that usually don't bother me. Would you say you felt this way. . . | 1 | 2 | 3 | 4 | BRPCES1 |
| 2. I did not feel like eating; my appetite was poor | 1 | 2 | 3 | 4 | BRPCES2 |
| 3. I felt that I could not shake off the blues even with help from my friends or family | 1 | 2 | 3 | 4 | BRPCES3 |
| 4. I felt that I was just as good as other people | 4 | 3 | 2 | 1 | BRPCES4 |
| 5. I had trouble keeping my mind on what I was doing | 1 | 2 | 3 | 4 | BRPCES5 |
| 6. I felt depressed | 1 | 2 | 3 | 4 | BRPCES6 |
| 7. I felt that everything I did was an effort | 1 | 2 | 3 | 4 | BRPCES7 |
| 8. I felt hopeful about the future | 4 | 3 | 2 | 1 | BRPCES8 |
| 9. I thought my life had been a failure | 1 | 2 | 3 | 4 | BRPCES9 |
| 10. I felt fearful | 1 | 2 | 3 | 4 | BRPCES10 |
| 11. My sleep was restless | 1 | 2 | 3 | 4 | BRPCES11 |
| 12. I was happy | 4 | 3 | 2 | 1 | BRPCES12 |
| 13. I talked less than usual | 1 | 2 | 3 | 4 | BRPCES13 |
| 14. I felt lonely | 1 | 2 | 3 | 4 | BRPCES14 |
| 15. People were unfriendly | 1 | 2 | 3 | 4 | BRPCES15 |
| 16. I enjoyed life | 4 | 3 | 2 | 1 | BRPCES16 |
| 17. I had crying spells | 1 | 2 | 3 | 4 | BRPCES17 |

| | | Rarely Or None Of The Time (Less Than <u>1 Day</u>) | Some Or A Little of The Time (1-2 Days) | Occasionally Or A Moderate Amount of Time (3-4 Days) | Most Or All Of The Time (5-7 Days) | |
|-----|--|--|--|---|---|----------|
| 18. | I felt sad | 1 | 2 | 3 | 4 | BRPCES18 |
| 19. | I felt that people disliked me | 1 | 2 | 3 | 4 | BRPCES19 |
| 20. | I could not get "going" | 1 | 2 | 3 | 4 | BRPCES20 |
| 21. | I felt alone or cut off from other people | 1 | 2 | 3 | 4 | BRPCES21 |

STATE-TRAIT ANXIETY (MODIFIED - STATE ONLY)

I am going to read you a number of statements which people have used to describe themselves.
As I read each statement, please give me the answer which seems to describe how you feel *right now*.

| | | Not at <u>All</u> | <u>Somewhat</u> | Moderately <u>So</u> | Very <u>Much So</u> | |
|-----|--|----------------------|-----------------|-------------------------|------------------------|---------|
| 1. | I feel calm. Would you say this describes how you feel. . . | 1 | 2 | 3 | 4 | BRPST1 |
| 2. | I feel secure | 1 | 2 | 3 | 4 | BRPST2 |
| 3. | I am tense | 1 | 2 | 3 | 4 | BRPST3 |
| 4. | I feel strained | 1 | 2 | 3 | 4 | BRPST4 |
| 5. | I feel at ease | 1 | 2 | 3 | 4 | BRPST5 |
| 6. | I feel upset | 1 | 2 | 3 | 4 | BRPST6 |
| 7. | I am presently worrying over possible misfortunes | 1 | 2 | 3 | 4 | BRPST7 |
| 8. | I feel satisfied | 1 | 2 | 3 | 4 | BRPST8 |
| 9. | I feel frightened | 1 | 2 | 3 | 4 | BRPST9 |
| 10. | I feel comfortable | 1 | 2 | 3 | 4 | BRPST10 |
| 11. | I feel self-confident | 1 | 2 | 3 | 4 | BRPST11 |
| 12. | I feel nervous | 1 | 2 | 3 | 4 | BRPST12 |
| 13. | I feel jittery | 1 | 2 | 3 | 4 | BRPST13 |
| 14. | I feel indecisive | 1 | 2 | 3 | 4 | BRPST14 |
| 15. | I feel relaxed | 1 | 2 | 3 | 4 | BRPST15 |
| 16. | I feel content | 1 | 2 | 3 | 4 | BRPST16 |
| 17. | I feel worried | 1 | 2 | 3 | 4 | BRPST17 |
| 18. | I feel confused | 1 | 2 | 3 | 4 | BRPST18 |
| 19. | I feel steady | 1 | 2 | 3 | 4 | BRPST19 |
| 20. | I feel pleasant | 1 | 2 | 3 | 4 | BRPST20 |

Thank you for your cooperation. Is there anything else you'd like to comment on that we have not covered in this interview?

TIME ENDED:

____/____ a.m./p.m
hour minutes

BRPHR
BRPMN

INTERVIEWER REMARKS

- | | | |
|----|---|-------------------------------|
| 1. | Did respondent experience or exhibit emotional or psychological problems during the interview? | BRPR1 |
| | Yes 1 (ANSWER A) | |
| | No 2 | |
| A. | What was the problem? _____ _____ _____ | BRPR1A1 BRPR1A2 BRPR1A3 |
| 2. | Were there any other problems during the interview? | BRPR2 |
| | Yes 1 (ANSWER A) | |
| | No 2 | |
| A. | What was the problem? _____ _____ _____ | BRPR2A1 BRPR2A2 BRPR2A3 |
| 3. | Was interview conducted in English or Spanish? | BRPR3 |
| | English 1 (ANSWER A) | |
| | Spanish 2 | |
| A. | How much trouble does respondent have understanding English? | BRPR3A |
| | None 1 | |
| | Some 2 | |
| | A great deal 3 | |
| 4. | Regardless of whether or not interview was completed in one session, did the respondent <i>want to</i> terminate interview before interview was finished? | BRPR4 |
| | Yes 1 (ANSWER A) | |
| | No 2 | |
| A. | At what points and why? _____ _____ _____ | BRPR4A1 BRPR4A2 BRPR4A3 |
| 5. | Did respondent need to complete interview over two or more sessions? | BRPR5 |
| | Yes 1 (ANSWER A) | |
| | No 2 | |
| A. | Reasons given for needing to break up interview _____ _____ | BRPR5A1 BRPR5A2 |

6. Date interview started:

____/____/____
(mo) (da) (yr)

BRPR6MO
BRPR6DA
BRPR6YR

7. Date interview completed:

____/____/____
(mo) (da) (yr)

BRPR7MO
BRPR7DA
BRPR7YR

8. Number of interviewing sessions needed to complete interview:

| | |
|-------------|---|
| One | 1 |
| Two | 2 |
| Three | 3 |
| Four | 4 |

BRPR8

9. Name and ID of interviewer:

NAME

I.D.

BRPR9

10. Total time spent interviewing:

____/____
hours minutes

BRPR10

11. Proxy questionnaire was answered by:

| | |
|--|---|
| Caregiving Daughter | 1 |
| Patient's Spouse | 2 |
| Other Daughter of Patient..... | 3 |
| Patient's Son..... | 4 |
| Other Relative (Specify _____)..... | 5 |
| NOT APPLICABLE; Patient completed questionnaire herself | 8 |

BRPR11

Interviewer Comments and observations not otherwise specified:

CODED _____

ENTERED _____

VERIFIED _____

Time Started
_____ am/pm

Time Ended
_____ am/pm

**Aging Families and Breast Cancer:
Multigenerational Issues**

Entrevista Con el Paciente

**Numero De Identificación Del Paciente:
(Patient ID #)**

TIME BEGUN:

____ / ____ a.m./p.m.

DATOS DE ANTECEDENTES
(BACKGROUND QUESTIONS)

1. ¿Cuál es su fecha de nacimiento?

____ / ____ / ____
(mes) (día) (año)

BRPS1MO
BRPS1DA
BRPS1YR

2. ¿Cuál es el grado más alto de instrucción escolar que usted ha completado?

Octavo grado o menos1
Algunos años de escuela superior2
Graduado de escuela superior o recipiente de diploma de equivalencia
general (GED)3
Algunos años de colegio4
Grado asociado5
Escuela vocacional o técnico6
Grado universitario (bachillerato)7
Algunos años de escuela graduada8
Diploma licenciado o profesional9

BRPS2

3. ¿Cómo se describe usted? ¿Diría usted que es...

Blanca1 (PREGUNTE A)
Negra o Afroamericana2 (PREGUNTE A)
Asiática o Isleopacífica3
De raza indígena-americana o alasqueña4
Otra (ESPECIFIQUE)5 (PREGUNTE A)

BRPS3

- A. ¿Es usted de descendencia Hispánica?

Sí1 (PREGUNTE B)
No2

BRPS3A

- B. ¿Se considera usted...

Puertorriqueña1
Dominicana2
Cubana3
Mejicana4
Ecuatoriana5
Colombiana6
Español o europeo7
De otra nacionalidad (ESPECIFIQUE)10

BRPS3B

4. Actualmente, ¿está usted empleado, desempleado, recibiendo beneficios por incapacidad, fuera de su trabajo por enfermedad u otra cosa?
- BRPS4
- Empleado1 (PREGUNTE A)
 Recibiendo beneficios por incapacidad.....2 (PREGUNTE C)
 Afuera de su trabajo por enfermedad.....3 (PREGUNTE C)
 Desempleado, despedido o buscando trabajo4 (PREGUNTE B)
 Jubilado5 (PREGUNTE C)
 Estudiando y no trabajando.....6 (PREGUNTE B)
 Ama de casa.....7 (PREGUNTE B)
 Otra (ESPECIFIQUE).....8 (PREGUNTE B)
- A. (SI EMPLEADO): ¿Cuántas horas trabaja por semana?
- BRPS4A
- _____ núm. de horas (Si menos de 35 horas, pase a la D. Si 35 o más, pase a la Preg. 5.)
- B. ¿Ha tenido alguna vez un trabajo que durara seis meses o más?
- BRPS4B
- Sí1
 No2 (Pase a la Preg. 8.)
- C. ¿En qué mes y año trabajo usted por última vez?
- BRPS4CMO
 BRPS4CYR
- _____/_____
 (mes) (año)
- D. (SI TRABAJA TIEMPO PARCIAL O NO TRABAJA): (¿Trabaja usted tiempo parcial o no trabaja) debido a su enfermedad?
- BRPS4D
- Sí1
 No2
5. ¿Qué tipo de trabajo (hace/hizo) usted? Es decir, ¿qué título (tiene/tenía) en su trabajo? (INDAGUE SI ES NECESARIO.) ¿Qué (hace/hacía) en su trabajo? ¿Cuáles (son/fueron) sus responsabilidades principales?
- BRPS5
- Ocupación: _____
 Título: _____
 Responsabilidades: _____

- A. ¿Qué clase de compañía o industria es esa? ¿Qué hacen en el lugar dónde usted (trabaja/trabajó)?
- BRPS5A
- _____

6. ¿Es/fue usted empleado en su propio negocio o práctica, o trabaja/trabajó sin sueldo en un negocio familiar (en su trabajo principal)?
- BRPS6
- Sí, empleado por si misma.....1
 No, trabaja/trabajó para otra persona.....2

7. ¿Cuál fue o cuál es su salario bruto anual? Le voy a leer una lista de cantidades de ingreso.
Le pido que me indique cuando me acerque a la categoría que incluya su ingreso.

BRPS7

\$5,000 o menos.....1
\$5,001 a \$10,0002
\$10,001 a \$15,0003
\$15,001 a \$20,0004
\$20,001 a \$25,0005

\$25,001 a \$30,0006
\$30,001 a \$40,0007
\$40,001 a \$50,0008
\$50,001 a \$60,0009
\$60,001 a \$70,00010

\$70,001 a \$80,00011
\$80,001 a \$90,00012
\$90,001 a \$100,00013
\$100,001 o más.....14

No sabe.....97

(PREGUNTE A)

Rehusa responder99

(PREGUNTE A)

- A. ¿Me puede decir si fue...

BRPS7A

Menos de \$25,000 al año, o.....1

Más de \$25,000 al año?.....2

NO SABE; REHUSO3

8. ¿Cuál es su estado civil?

BRPS8

Casada1

(PREGUNTE A)

(SI EXPRESADO POR EL ENTREVISTADO):

Viviendo con su pareja2

(PREGUNTE A)

Divorciada3

Separada4

Enviudada.....5

Soltera/Nunca casada6

- A. ¿Cuánto tiempo hace que está casada/viviendo con su pareja?

BRPS8A

núm. de años

9. ¿Cuántos hijos tiene usted?

BRPS9

núm. de hijos

10. Me puede decir, por favor, ¿quién vive con usted en su hogar? (PREGUNTE DEL A AL C PARA CADA PERSONA EN EL HOGAR.) (SI HA CAMBIADO LA COMPOSICION DEL HOGAR DE LO USUAL, CODIFIQUE DE ACUERDO A LA COMPOSICION EN EL ULTIMO MES.) INDAGUE:
¿Alguien más?

A. ¿Cuál es el parentesco
Entre usted y

B. Sexo
Varón Hembra

C. ¿Qué
edad tiene?

Persona 1 _____

1 2

BRPS10R1
BRPS10S1
BRPS10A1

Persona 2 _____

1 2

BRPS10R2
BRPS10S2
BRPS10A2

Persona 3 _____

1 2

BRPS10R3
BRPS10S3
BRPS10A3

Persona 4 _____

1 2

BRPS10R4
BRPS10S4
BRPS10A4

Persona 5 _____

1 2

BRPS10R5
BRPS10S5
BRPS10A5

Persona 6 _____

1 2

BRPS10R6
BRPS10S6
BRPS10A6

Persona 7 _____

1 2

BRPS10R7
BRPS10S7
BRPS10A7

Persona 8 _____

1 2

BRPS10R8
BRPS10S8
BRPS10A8

11. Incluyéndose a usted, el número total de
personas que viven en su hogar es: _____

BRPS11

RED DE RELACIONES (ABREVIADO)
(NETWORK OF RELATIONSHIPS -- ABBREVIATED)

Nos interesa saber como la enfermedad cambia las relaciones. En la siguiente serie de preguntas, deseamos saber como ha sido la relación con su hija *desde su diagnóstico* y como fue *antes de su diagnóstico*.

| | | De Ningún Modo o <u>Poquito</u> | <u>Un poco</u> | <u>Mucha</u> | Extrema- <u>demente</u> | Lo <u>Máximo</u> | <u>DNA</u> | |
|----|--|---------------------------------------|----------------|--------------|----------------------------|---------------------|------------|---------|
| 1. | ¿Cuánto se enojan usted y su hija una con la otra... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR1A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR1B |
| 2. | ¿Cuán satisfecha está usted con la relación entre usted y su hija... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR2A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR2B |
| 3. | ¿Hasta qué punto le cuenta usted todo a su hija... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR3A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR3B |
| 4. | ¿Cuánto le ayuda usted hacer cosas a su hija que ella no puede hacer por sí misma... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR4A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR4B |
| 5. | ¿Cuánto le trata su hija a usted con admiración y respeto... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR5A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR5B |
| 6. | ¿Cuánto difieren de opinión usted y su hija... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR6A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR6B |

| | | De Ningún Modo o <u>Poquito</u> | <u>Un poco</u> | <u>Mucha</u> | <u>Extrema- demente</u> | <u>Lo Máximo</u> | <u>DNA</u> | |
|-----|--|---------------------------------------|----------------|--------------|-----------------------------|----------------------|------------|----------|
| 7. | ¿Cuán feliz está usted con la manera en qué son las cosas entre usted y su hija... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR7A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR7B |
| 8. | ¿Cuánto comparte usted sus secretos y sentimientos privados con su hija... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR8A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR8B |
| 9. | ¿Cuánto protege y vela usted por su hija... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR9A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR9B |
| 10. | ¿Hasta qué punto le trata su hija a usted cómo una personal hábil... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR10A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR10B |
| 11. | ¿Cuánto discuten usted y su hija... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR11A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR11B |
| 12. | ¿Cuán buena es su relación con su hija... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR12A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR12B |
| 13. | ¿Cuánto habla con su hija sobre asuntos que no desea que otros sepan... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR13A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR13B |

| | De Ningún Modo o <u>Poquito</u> | <u>Un poco</u> | <u>Mucha</u> | <u>Extrema- demente</u> | <u>Lo Máximo</u> | <u>DNA</u> | |
|---|---------------------------------------|-------------------------------|--------------------------|-----------------------------|-------------------------------------|------------|----------|
| 14. ¿Cuánto cuida usted de su hija... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR14A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR14B |
| 15. ¿Cuánto le gusta o aprueba su hija de las cosas que usted hace... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR15A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR15B |
| 16. ¿Cuán apegada es su relación con su hija... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR16A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR16B |
| | <u>Hija casi siempre hace</u> | <u>Hija hace a menudo</u> | <u>Casi lo mismo</u> | <u>Yo hago a menudo</u> | <u>Casi siempre hago yo</u> | <u>DNA</u> | |
| 17. Entre usted y su hija, ¿quién le dice a la otra lo que debe hacer con más frecuencia... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR17A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR17B |
| 18. Entre usted y su hija, ¿cuál de las dos tiende a ser la jefa en la relación... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR18A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR18B |
| 19. En su relación con su hija, ¿quién tiende a asumir el mando y decidir lo que se debe hacer... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR19A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRPNR19B |

OBLIGACIÓN FILIAL

En esta siguiente serie de declaraciones le voy a hacer preguntas acerca de sus opiniones con respecto a la ayuda en el hogar.

1. Los hijos casados deben de vivir cerca de sus padres para proveer cuidado. ¿Está usted...

Fuertemente de acuerdo 5
Un poco de acuerdo 4
Ni de acuerdo ni en desacuerdo 3
Un poco en desacuerdo 2
Fuertemente en desacuerdo 1

BRPFO1

2. Los padres no deben de contar con que sus hijos le hagan tareas. ¿Está usted...

Fuertemente de acuerdo 5
Un poco de acuerdo 4
Ni de acuerdo ni en desacuerdo 3
Un poco en desacuerdo 2
Fuertemente en desacuerdo 1

BRPFO2

3. Los padres deben de contar con que sus hijos adultos les ayuden. ¿Está usted...

Fuertemente de acuerdo 5
Un poco de acuerdo 4
Ni de acuerdo ni en desacuerdo 3
Un poco en desacuerdo 2
Fuertemente en desacuerdo 1

BRPFO3

4. Es el deber de un(a) hijo(a) ayudar a sus padres. ¿Está usted...

Fuertemente de acuerdo 5
Un poco de acuerdo 4
Ni de acuerdo ni en desacuerdo 3
Un poco en desacuerdo 2
Fuertemente en desacuerdo 1

BRPFO4

5. Es preferible pagarle a un profesional para que ayude a proveer cuidado. ¿Está usted...

Fuertemente de acuerdo 5
Un poco de acuerdo 4
Ni de acuerdo ni en desacuerdo 3
Un poco en desacuerdo 2
Fuertemente en desacuerdo 1

BRPFO5

6. Pagar por ayuda profesional significa que un pariente no está tomando responsabilidad. ¿Está usted...

Fuertemente de acuerdo 5
Un poco de acuerdo 4
Ni de acuerdo ni en desacuerdo 3
Un poco en desacuerdo 2
Fuertemente en desacuerdo 1

BRPFO6

7. Es mejor dejar un trabajo para proveer cuidado que pagarle a un profesional. ¿Está usted...

Fuertemente de acuerdo 5
Un poco de acuerdo 4
Ni de acuerdo ni en desacuerdo 3
Un poco en desacuerdo 2
Fuertemente en desacuerdo 1

BRPFO7

ACTIVIDADES COTIDIANAS

Como resultado de una enfermedad, las personas frecuentemente tienen que cambiar sus rutinas. Para cada de las actividades que le voy a leer, por favor dígame si usted la lleva a cabo por sí misma(o), si usted obtiene ayuda con la actividad o si alguien le hacía esto aún antes de su enfermedad. **(INDAGUE CUANDO SEA NECESARIO PARA DETERMINAR SI LA AYUDA RECIBIDA ESTA RELACIONADA CON LA ENFERMEDAD.)**

1. ¿Quién le hace sus quehaceres domésticos leves tales como sacar el polvo, lavar los platos y vestir las camas?
¿Hace esto por sí misma, obtiene ayuda para hacer estas cosas o se las hace alguien por usted?

BRPDL1

| | | |
|--|---|------------------|
| Las hace por sí misma..... | 1 | (PREGUNTE B) |
| Obtiene ayuda | 2 | (PREGUNTE A & B) |
| Alguien le hace estas cosas debido a enfermedad..... | 3 | (PREGUNTE A & B) |
| Otra persona siempre ha hecho estas cosas (no porque el enfermedad)..... | 4 | (PREGUNTE A) |
| No se hacen estas cosas..... | 5 | (PREGUNTE B) |

A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL1A

| | |
|--|----|
| Esposo..... | 1 |
| Hija quien provee cuidado..... | 2 |
| Otra hija..... | 3 |
| Hijo..... | 4 |
| Nuera | 5 |
| Yerno | 6 |
| Hermano | 7 |
| Hermana | 8 |
| Otro pariente (ESPECIFIQUE: _____) | 9 |
| Amiga(o) | 10 |
| Enfermera o asistente de salud | 11 |
| Compañera(o) de trabajo/empleado | 12 |
| Terapista..... | 13 |
| Trabajador(a) social..... | 14 |
| Médico/Psiquiatra..... | 15 |
| Otra persona (ESPECIFIQUE: _____) | 16 |

- B. ¿Necesita (más) ayuda? (Si actividades no hechas, preguntar: ¿si fuera hecho, necesitara alguna ayuda?)

BRPDL1B

| | |
|---------|---|
| Si..... | 1 |
| No..... | 2 |

2. ¿Quién le hace sus quehaceres domésticos pesados tales como limpiar los pisos, pasar la aspiradora, lavar la ropa o limpiar el cuarto de baño? ¿Hace esto por sí misma, obtiene ayuda para hacer estas cosas o se las hace alguien por usted?

BRPDL2

| | | |
|--|---|------------------|
| Las hace por sí misma..... | 1 | (PREGUNTE B) |
| Obtiene ayuda | 2 | (PREGUNTE A & B) |
| Alguien le hace estas cosas debido a enfermedad..... | 3 | (PREGUNTE A & B) |
| Otra persona siempre ha hecho estas cosas (no porque el enfermedad)..... | 4 | (PREGUNTE A) |
| No se hacen estas cosas..... | 5 | (PREGUNTE B) |

A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL2A

| | |
|---------------------------------------|----|
| Esposo..... | 1 |
| Hija quien provee cuidado..... | 2 |
| Otra hija..... | 3 |
| Hijo..... | 4 |
| Nuera..... | 5 |
| Yerno..... | 6 |
| Hermano..... | 7 |
| Hermana..... | 8 |
| Otro pariente (ESPECIFIQUE:.....) | 9 |
| Amiga(o)..... | 10 |
| Enfermera o asistente de salud..... | 11 |
| Compañera(o) de trabajo/empleado..... | 12 |
| Terapista..... | 13 |
| Trabajador(a) social..... | 14 |
| Médico/Psiquiatra..... | 15 |
| Otra persona (ESPECIFIQUE:.....) | 16 |

B. ¿Necesita (más) ayuda? (Si actividades no hechas, preguntar: ¿si fuera hecho, necesitara alguna ayuda?)

BRPDL2B

| | |
|---------|---|
| Si..... | 1 |
| No..... | 2 |

3. ¿Quién le prepara y le cocina las comidas? ¿Hace esto por sí misma, obtiene ayuda para hacer esto o se lo hace alguien por usted?

BRPDL3

| | | |
|--|---|------------------|
| Las hace por sí misma..... | 1 | (PREGUNTE B) |
| Obtiene ayuda..... | 2 | (PREGUNTE A & B) |
| Alguien le hace estas cosas debido a enfermedad..... | 3 | (PREGUNTE A & B) |
| Otra persona siempre ha hecho estas cosas (no porque el enfermedad)..... | 4 | (PREGUNTE A) |
| No se hacen estas cosas..... | 5 | (PREGUNTE B) |

A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL3A

| | |
|---------------------------------------|----|
| Esposo..... | 1 |
| Hija quien provee cuidado..... | 2 |
| Otra hija..... | 3 |
| Hijo..... | 4 |
| Nuera..... | 5 |
| Yerno..... | 6 |
| Hermano..... | 7 |
| Hermana..... | 8 |
| Otro pariente (ESPECIFIQUE:.....) | 9 |
| Amiga(o)..... | 10 |
| Enfermera o asistente de salud..... | 11 |
| Compañera(o) de trabajo/empleado..... | 12 |
| Terapista..... | 13 |
| Trabajador(a) social..... | 14 |
| Médico/Psiquiatra..... | 15 |
| Otra persona (ESPECIFIQUE:.....) | 16 |

B. ¿Necesita (más) ayuda? (Si actividades no hechas, preguntar: ¿si fuera hecho, necesitara alguna ayuda?)

BRPDL3B

| | |
|---------|---|
| Si..... | 1 |
| No..... | 2 |

4. ¿Quién le compra la ropa y los artículos para el hogar? ¿Hace esto por sí misma, obtiene ayuda para hacer esto o se lo hace alguien por usted?

BRPDL4

- Las hace por sí misma.....1 (PREGUNTE B)
 Obtiene ayuda2 (PREGUNTE A & B)
 Alguien le hace estas cosas debido a enfermedad.....3 (PREGUNTE A & B)
 Otra persona siempre ha hecho estas cosas (no porque el enfermedad).....4 (PREGUNTE A)
 No se hacen estas cosas.....5 (PREGUNTE B)

A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL4A

- Esposo1
 Hija quien provee cuidado.....2
 Otra hija.....3
 Hijo.....4
 Nuera5
 Yerno.....6
 Hermano7
 Hermana8
 Otro pariente (ESPECIFIQUE: _____)9
 Amiga(o)10
 Enfermera o asistente de salud11
 Compañera(o) de trabajo/empleado12
 Terapeuta.....13
 Trabajador(a) social.....14
 Médico/Psiquiatra.....15
 Otra persona (ESPECIFIQUE: _____)16

B. ¿Necesita (más) ayuda? (Si actividades no hechas, preguntar: ¿si fuera hecho, necesitara alguna ayuda?)

BRPDL4B

- Si.....1
 No.....2

5. ¿Quién le hace la compra de comestibles? ¿Hace esto por sí misma, obtiene ayuda para hacer esto o se lo hace alguien por usted?

BRPDL5

- Las hace por sí misma.....1 (PREGUNTE B)
 Obtiene ayuda2 (PREGUNTE A & B)
 Alguien le hace estas cosas debido a enfermedad.....3 (PREGUNTE A & B)
 Otra persona siempre ha hecho estas cosas (no porque el enfermedad).....4 (PREGUNTE A)
 No se hacen estas cosas.....5 (PREGUNTE B)

A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL5A

- Esposo.....1
 Hija quien provee cuidado2
 Otra hija.....3
 Hijo.....4
 Nuera5
 Yerno.....6
 Hermano7
 Hermana8
 Otro pariente (ESPECIFIQUE: _____)9
 Amiga(o)10
 Enfermera o asistente de salud11
 Compañera(o) de trabajo/empleado12
 Terapeuta.....13
 Trabajador(a) social.....14
 Médico/Psiquiatra.....15
 Otra persona (ESPECIFIQUE: _____)16

B. ¿Necesita (más) ayuda? (Si actividades no hechas, preguntar: ¿si fuera hecho, necesitara alguna ayuda?)

BRPDL5B

Si.....1
No.....2

6. ¿Puede bañarse por sí misma o le ayuda alguien?

BRPDL6

Las hace por sí misma.....1 (PREGUNTE B)
Obtiene ayuda2 (PREGUNTE A & B)
Alguien le hace estas cosas debido a enfermedad.....3 (PREGUNTE A & B)
Otra persona siempre ha hecho estas cosas (no porque el enfermedad).....4 (PREGUNTE A)
No se hacen estas cosas.....5 (PREGUNTE B)

A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL6A

Esposo.....1
Hija quien provee cuidado.....2
Otra hija.....3
Hijo.....4
Nuera.....5
Yerno.....6
Hermano.....7
Hermana.....8
Otro pariente (ESPECIFIQUE:.....).....9
Amiga(o).....10
Enfermera o asistente de salud11
Compañera(o) de trabajo/empleada12
Terapeuta.....13
Trabajador(a) social.....14
Médico/Psiquiatra.....15
Otra persona (ESPECIFIQUE:.....).....16

B. ¿Necesita (más) ayuda? (Si actividades no hechas, preguntar: ¿si fuera hecho, necesitara alguna ayuda?)

BRPDL6B

Si.....1
No2

7. ¿Lleva a cabo usted algunas tareas relacionadas con el cuidado de su salud en la casa tales como mantenerse al tanto de los medicamentos recetados o cambiarse los vendajes? ¿Hace esto por sí misma, obtiene ayuda para hacer esto o se lo hace alguien por usted?

BRPDL7

Las hace por sí misma.....1 (PREGUNTE B)
Obtiene ayuda2 (PREGUNTE A & B)
Alguien le hace estas cosas debido a enfermedad.....3 (PREGUNTE A & B)
Otra persona siempre ha hecho estas cosas (no porque el enfermedad).....4 (PREGUNTE A)
No se hacen estas cosas.....5 (PREGUNTE B)

A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL7A

- Esposo.....1
- Hija quien provee cuidado.....2
- Otra hija.....3
- Hijo.....4
- Nuera.....5
- Yerno.....6
- Hermano.....7
- Hermana.....8
- Otro pariente (ESPECIFIQUE: _____).....9
- Amiga(o).....10
- Enfermera o asistente de salud.....11
- Compañera(o) de trabajo/empleado.....12
- Terapeuta.....13
- Trabajador(a) social.....14
- Médico/Psiquiatra.....15
- Otra persona (ESPECIFIQUE: _____).....16

B. ¿Necesita (más) ayuda? (Si actividades no hechas, preguntar: ¿si fuera hecho, necesitara alguna ayuda?)

BRPDL7B

- Si.....1
- No.....2

8. ¿Se viste por sí misma o le ayuda alguien?

BRPDL8

- Las hace por sí misma.....1 (PREGUNTE B)
- Obtiene ayuda.....2 (PREGUNTE A & B)
- Alguien le hace estas cosas debido a enfermedad.....3 (PREGUNTE A & B)
- Otra persona siempre ha hecho estas cosas (no porque el enfermedad).....4 (PREGUNTE A)
- No se hacen estas cosas.....5 (PREGUNTE B)

A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL8A

- Esposo.....1
- Hija quien provee cuidado.....2
- Otra hija.....3
- Hijo.....4
- Nuera.....5
- Yerno.....6
- Hermano.....7
- Hermana.....8
- Otro pariente (ESPECIFIQUE: _____).....9
- Amiga(o).....10
- Enfermera o asistente de salud.....11
- Compañera(o) de trabajo/empleado.....12
- Terapeuta.....13
- Trabajador(a) social.....14
- Médico/Psiquiatra.....15
- Otra persona (ESPECIFIQUE: _____).....16

B. ¿Necesita (más) ayuda? (Si actividades no hechas, preguntar: ¿si fuera hecho, necesitara alguna ayuda?)

BRPDL8B

- Si.....1
- No.....2

9. ¿Puede usar el inodoro por sí misma o le ayuda alguien?

BRPDL9

- | | | |
|--|---|------------------|
| Las hace por sí misma..... | 1 | (PREGUNTE B) |
| Obtiene ayuda | 2 | (PREGUNTE A & B) |
| Alguien le hace estas cosas debido a enfermedad..... | 3 | (PREGUNTE A & B) |
| Otra persona siempre ha hecho estas cosas (no porque el enfermedad)..... | 4 | (PREGUNTE A) |
| No se hacen estas cosas..... | 5 | (PREGUNTE B) |

A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL9A

- | | |
|--|----|
| Esposo..... | 1 |
| Hija quien provee cuidado..... | 2 |
| Otra hija..... | 3 |
| Hijo..... | 4 |
| Nuera..... | 5 |
| Yerno..... | 6 |
| Hermano..... | 7 |
| Hermana..... | 8 |
| Otro pariente (ESPECIFIQUE:.....) | 9 |
| Amiga(o)..... | 10 |
| Enfermera o asistente de salud..... | 11 |
| Compañera(o) de trabajo/empleador..... | 12 |
| Terapeuta..... | 13 |
| Trabajador(a) social..... | 14 |
| Médico/Psiquiatra..... | 15 |
| Otra persona (ESPECIFIQUE:.....) | 16 |

B. ¿Necesita (más) ayuda? (Si actividades no hechas, preguntar: ¿si fuera hecho, necesitara alguna ayuda?)

BRPDL9B

- | | |
|---------|---|
| Si..... | 1 |
| No..... | 2 |

10. ¿Puede acostarse y levantarse de la cama o sentarse y levantarse de una silla por sí misma o le ayuda alguien?

BRPDL10

- | | | |
|--|---|------------------|
| Las hace por sí misma..... | 1 | (PREGUNTE B) |
| Obtiene ayuda | 2 | (PREGUNTE A & B) |
| Alguien le hace estas cosas debido a enfermedad..... | 3 | (PREGUNTE A & B) |
| Otra persona siempre ha hecho estas cosas (no porque el enfermedad)..... | 4 | (PREGUNTE A) |
| No se hacen estas cosas..... | 5 | (PREGUNTE B) |

A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL10A

- | | |
|--|----|
| Esposo..... | 1 |
| Hija quien provee cuidado..... | 2 |
| Otra hija..... | 3 |
| Hijo..... | 4 |
| Nuera..... | 5 |
| Yerno..... | 6 |
| Hermano..... | 7 |
| Hermana..... | 8 |
| Otro pariente (ESPECIFIQUE:.....) | 9 |
| Amiga(o)..... | 10 |
| Enfermera o asistente de salud..... | 11 |
| Compañera(o) de trabajo/empleador..... | 12 |
| Terapeuta..... | 13 |
| Trabajador(a) social..... | 14 |
| Médico/Psiquiatra..... | 15 |
| Otra persona (ESPECIFIQUE:.....) | 16 |

B. ¿Necesita (más) ayuda? (Si actividades no hechas, preguntar: ¿si fuera hecho, necesitara alguna ayuda?)

BRPDL10B

Si.....1

No2

11. Cuando viaja al hospital para sus citas médicas, ¿usualmente va sola o le acompaña alguien?

BRPDL11

Las hace por sí misma.....1 (PREGUNTE B)
Obtiene ayuda2 (PREGUNTE A & B)
Alguien le hace estas cosas debido a enfermedad.....3 (PREGUNTE A & B)
Otra persona siempre ha hecho estas cosas (no porque el enfermedad).....4 (PREGUNTE A)
No se hacen estas cosas.....5 (PREGUNTE B)

A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL11A

Esposo.....1
Hija quien provee cuidado.....2
Otra hija.....3
Hijo.....4
Nuera.....5
Yerno.....6
Hermano.....7
Hermana.....8
Otro pariente (ESPECIFIQUE: _____).....9
Amiga(o)10
Enfermera o asistente de salud.....11
Compañera(o) de trabajo/empleada12
Terapeuta.....13
Trabajador(a) social.....14
Médico/Psiquiatra.....15
Otra persona (ESPECIFIQUE: _____).....16

B. ¿Necesita (más) ayuda? (Si actividades no hechas, preguntar: ¿si fuera hecho, necesitara alguna ayuda?)

BRPDL11B

Si.....1

No.....2

12. Cuando viaja con otros propósitos tales como a trabajar, visitar o para hacer mandados, ¿usualmente va sola o le acompaña alguien?

BRPDL12

Las hace por sí misma.....1 (PREGUNTE B)
Obtiene ayuda2 (PREGUNTE A & B)
Alguien le hace estas cosas debido a enfermedad.....3 (PREGUNTE A & B)
Otra persona siempre ha hecho estas cosas (no porque el enfermedad).....4 (PREGUNTE A)
No se hacen estas cosas.....5 (PREGUNTE B)

A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL12A

- Esposo.....1
- Hija quien provee cuidado.....2
- Otra hija.....3
- Hijo.....4
- Nuera.....5
- Yerno.....6
- Hermano.....7
- Hermana.....8
- Otro pariente (ESPECIFIQUE:.....).....9
- Amiga(o).....10
- Enfermera o asistente de salud.....11
- Compañera(o) de trabajo/empleado.....12
- Terapista.....13
- Trabajador(a) social.....14
- Médico/Psiquiatra.....15
- Otra persona (ESPECIFIQUE:.....).....16

B. ¿Necesita (más) ayuda? (Si actividades no hechas, preguntar: ¿si fuera hecho, necesitara alguna ayuda?)

BRPDL12B

- Si.....1
- No.....2

13. ¿Llena usted formularios tales como reclamos de seguro, formularios médicos o solicitudes misma, obtiene ayuda o hace alguien para beneficios financieros por sí esto por usted?

BRPDL13

- Las hace por sí misma.....1 (PREGUNTE B)
- Obtiene ayuda.....2 (PREGUNTE A & B)
- Alguien le hace estas cosas debido a enfermedad.....3 (PREGUNTE A & B)
- Otra persona siempre ha hecho estas cosas (no porque el enfermedad).....4 (PREGUNTE A)
- No se hacen estas cosas.....5 (PREGUNTE B)

A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL13A

- Esposo.....1
- Hija quien provee cuidado.....2
- Otra hija.....3
- Hijo.....4
- Nuera.....5
- Yerno.....6
- Hermano.....7
- Hermana.....8
- Otro pariente (ESPECIFIQUE:.....).....9
- Amiga(o).....10
- Enfermera o asistente de salud.....11
- Compañera(o) de trabajo/empleado.....12
- Terapista.....13
- Trabajador(a) social.....14
- Médico/Psiquiatra.....15
- tra persona (ESPECIFIQUE:.....).....16

B. ¿Necesita (más) ayuda? (Si actividades no hechas, preguntar: ¿si fuera hecho, necesitara alguna ayuda?)

BRPDL13B

- Si.....1
- No.....2

14. ¿Maneja usted sus asuntos bancarios tales como hacer depósitos y retiros, pagar las cuentas y mantener una cuenta de cheques por sí misma, obtiene ayuda o hace alguien esto por usted?

BRPDL14

Las hace por sí misma1 (PREGUNTE B)
Obtiene ayuda2 (PREGUNTE A & B)
Alguien le hace estas cosas debido a enfermedad3 (PREGUNTE A & B)
Otra persona siempre ha hecho estas cosas (no porque el enfermedad)4 (PREGUNTE A)
No se hacen estas cosas5 (PREGUNTE B)

- A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL14A

Esposo1
Hija quien provee cuidado2
Otra hija3
Hijo4
Nuera5
Yerno6
Hermano7
Hermana8
Otro pariente (ESPECIFIQUE: _____)9
Amiga(o)10
Enfermera o asistente de salud11
Compañera(o) de trabajo/empleo12
Terapeuta13
Trabajador(a) social14
Médico/Psiquiatra15
Otra persona (ESPECIFIQUE: _____)16

- B. ¿Necesita (más) ayuda? (Si actividades no hechas, preguntar: ¿si fuera hecho, necesitara alguna ayuda?)

BRPDL14B

Si1
No2

15. ¿Necesita ayuda o está obteniendo ayuda para conseguir información acerca de su enfermedad y tratamiento?

BRPDL15

No tiene necesidad1
Tiene ayuda haciendo este actividad2 (PREGUNTE A & B)
Necesita ayuda3

- A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.)

BRPDL15A

Esposo1
Hija quien provee cuidado2
Otra hija3
Hijo4
Nuera5
Yerno6
Hermano7
Hermana8
Otro pariente (ESPECIFIQUE: _____)9
Amiga(o)10
Enfermera o asistente de salud11
Compañera(o) de trabajo/empleo12
Terapeuta13
Trabajador(a) social14
Médico/Psiquiatra15
Otra persona (ESPECIFIQUE: _____)16

| | | |
|--|----|------------------|
| B. ¿Necesita más ayuda? | | BRPDL15B |
| Si..... | 1 | |
| No | 2 | |
| 16. ¿Necesita o está obteniendo consejería financiera relacionada con su enfermedad? | | BRPDL16 |
| No tiene necesidad | 1 | |
| Tiene ayuda haciendo esta actividad..... | 2 | (PREGUNTE A & B) |
| Necesita ayuda | 3 | |
| A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.) | | BRPDL16A |
| Esposo..... | 1 | |
| Hija quien provee cuidado..... | 2 | |
| Otra hija..... | 3 | |
| Hijo..... | 4 | |
| Nuera | 5 | |
| Yerno..... | 6 | |
| Hermano | 7 | |
| Hermana | 8 | |
| Otro pariente (ESPECIFIQUE: _____) | 9 | |
| Amiga(o) | 10 | |
| Enfermera o asistente de salud | 11 | |
| Compañera(o) de trabajo/empleada | 12 | |
| Terapeuta..... | 13 | |
| Trabajador(a) social..... | 14 | |
| Médico/Psiquiatra..... | 15 | |
| Otra persona (ESPECIFIQUE: _____) | 16 | |
| B. ¿Necesita más ayuda? | | BRPDL16B |
| Si..... | 1 | |
| No | 2 | |
| 17. ¿Necesita o está obteniendo consejería legal relacionada con su enfermedad tal como autoridad como ejecutor? | | BRPDL17 |
| No tiene necesidad | 1 | |
| Tiene ayuda haciendo esta actividad..... | 2 | (PREGUNTE A & B) |
| Necesita ayuda | 3 | |
| A. ¿Quién le ayuda? (HAGA UN CIRCULO ALREDEDOR DE TODOS LOS QUE APLIQUEN.) | | BRPDL17A |
| Esposo..... | 1 | |
| Hija quien provee cuidado..... | 2 | |
| Otra hija..... | 3 | |
| Hijo..... | 4 | |
| Nuera | 5 | |
| Yerno..... | 6 | |
| Hermano | 7 | |
| Hermana | 8 | |
| Otro pariente (ESPECIFIQUE: _____) | 9 | |
| Amiga(o) | 10 | |
| Enfermera o asistente de salud | 11 | |
| Compañera(o) de trabajo/empleada | 12 | |
| Terapeuta..... | 13 | |
| Trabajador(a) social..... | 14 | |
| Médico/Psiquiatra..... | 15 | |
| Otra persona (ESPECIFIQUE: _____) | 16 | |

B. ¿Necesita más ayuda?

Si.....1
No2

BRPDL17B

PRONOSTICABILIDAD DE LA ENFERMEDAD
(ILLNESS PREDICTABILITY)

- | | | |
|----|---|--------|
| 1. | Generalmente, conozco cuando voy a tener un buen día o un mal día. ¿Está usted... | BRPIP1 |
| | <p>Fuertemente de acuerdo 5</p> <p>Un poco de acuerdo 4</p> <p>Ni de acuerdo ni en desacuerdo 3</p> <p>Un poco en desacuerdo 2</p> <p>Fuertemente en desacuerdo 1</p> | |
| 2. | Es evidente para mí cuando mi enfermedad está mejorándose o empeorándose. ¿Está usted... | BRPIP2 |
| | <p>Fuertemente de acuerdo 5</p> <p>Un poco de acuerdo 4</p> <p>Ni de acuerdo ni en desacuerdo 3</p> <p>Un poco en desacuerdo 2</p> <p>Fuertemente en desacuerdo 1</p> | |
| 3. | Generalmente, puedo predecir el curso de mi enfermedad. ¿Está usted... | BRPIP3 |
| | <p>Fuertemente de acuerdo 5</p> <p>Un poco de acuerdo 4</p> <p>Ni de acuerdo ni en desacuerdo 3</p> <p>Un poco en desacuerdo 2</p> <p>Fuertemente en desacuerdo 1</p> | |
| 4. | Mi angustia física es pronosticable. ¿Está usted... | BRPIP4 |
| | <p>Fuertemente de acuerdo 5</p> <p>Un poco de acuerdo 4</p> <p>Ni de acuerdo ni en desacuerdo 3</p> <p>Un poco en desacuerdo 2</p> <p>Fuertemente en desacuerdo 1</p> | |

CONTROL SOBRE LA ENFERMEDAD
(ILLNESS CONTROL)

- | | | |
|----|---|--------|
| 5. | ¿Cuánto control personal piensa usted que tiene sobre la cantidad de cansancio que experimenta de día a día? ¿Diría que tiene... | BRPIC5 |
| | <p>Ningún control 5</p> <p>Muy poco control 4</p> <p>Una cantidad moderada de control 3</p> <p>Bastante control 2</p> <p>Extremo control 1</p> <p>NO APLICA 8</p> | |
| 6. | ¿Cuánto control personal piensa usted que tiene sobre la cantidad de incomodidad que experimenta de día a día? ¿Diría que tiene... | BRPIC6 |
| | <p>Ningún control 5</p> <p>Muy poco control 4</p> <p>Una cantidad moderada de control 3</p> <p>Bastante control 2</p> <p>Extremo control 1</p> <p>NO APLICA 8</p> | |

7. ¿Cuánto control personal piensa usted que tiene sobre la cantidad de inmovilidad que experimenta de día a día? ¿Diría que tiene...

BRPIC7

Ningún control 5
 Muy poco control..... 4
 Una cantidad moderada de control 3
 Bastante control 2
 Extremo control 1
 NO APLICA 8

8. ¿Cuánto control personal piensa usted que tiene sobre la cantidad de dolor que experimenta de día a día? ¿Diría que tiene...

BRPIC8

Ningún control 5
 Muy poco control..... 4
 Una cantidad moderada de control 3
 Bastante control 2
 Extremo control 1
 NO APLICA 8

9. ¿Cuánto control personal cree usted que tiene sobre el curso a largo plazo de su enfermedad; es decir, si mejorará o, al menos, no empeorará en el futuro? ¿Diría que tiene...

BRPIC9

Ningún control 5
 Muy poco control..... 4
 Una cantidad moderada de control 3
 Bastante control 2
 Extremo control 1
 NO APLICA 8

10. ¿Cuánto control personal piensa usted que tiene sobre el cuidado médico y el tratamiento de su enfermedad? ¿Diría que tiene...

BRPIC10

Ningún control 5
 Muy poco control..... 4
 Una cantidad moderada de control 3
 Bastante control 2
 Extremo control 1
 NO APLICA 8

CES-D SCALE

Ahora le voy a leer una lista de formas en que usted se pudo sentir o en que se comportó durante la semana pasada. Cuando lea cada declaración, por favor dígame que categoría describe mejor cuan a menudo usted se sintió de esa manera **durante la semana pasada**.

| | Raramente O Ningún Tiempo (Menos que un día) | Algún Tiempo (1-2 días) | Moderado Tiempo (3-4 días) | Siempre (5-7 días) | |
|---|--|-------------------------------|----------------------------------|-----------------------|----------|
| <i>Durante la semana pasada:</i> | | | | | |
| 1. Estuve molestanda por cosas que generalmente no me molestan. ¿Diría usted que se sintió de esta manera... | 1 | 2 | 3 | 4 | BRPCES1 |
| 2. No tuve ganas de comer; Mi apetito fue pobre | 1 | 2 | 3 | 4 | BRPCES2 |
| 3. Me sentí que no podía quitarme de encima la melancolía aún con la ayuda de mis amigas o familia | 1 | 2 | 3 | 4 | BRPCES3 |
| 4. Me consideré tan valiosa como la demás gente | 4 | 3 | 2 | 1 | BRPCES4 |
| 5. Tuve problemas manteniendo la concentración en lo que estaba haciendo | 1 | 2 | 3 | 4 | BRPCES5 |
| 6. Me sentí deprimida | 1 | 2 | 3 | 4 | BRPCES6 |
| 7. Me sentí que todo lo que hacía me costaba esfuerzo | 1 | 2 | 3 | 4 | BRPCES7 |
| 8. Me sentí con esperanza en el futuro | 4 | 3 | 2 | 1 | BRPCES8 |
| 8. Pensé que mi vida había sido un fracaso | 1 | 2 | 3 | 4 | BRPCES9 |
| 9. Me sentí temerosa | 1 | 2 | 3 | 4 | BRPCES10 |
| 10. Mi sueño fue inquieto | 1 | 2 | 3 | 4 | BRPCES11 |
| 11. Fui feliz | 4 | 3 | 2 | 1 | BRPCES12 |
| 12. Hablé menos de lo usual | 1 | 2 | 3 | 4 | BRPCES13 |
| 13. Me sentí solitaria | 1 | 2 | 3 | 4 | BRPCES14 |
| 14. Encontré que la gente no fue amistosa | 1 | 2 | 3 | 4 | BRPCES15 |
| 16. Disfruté de la vida | 4 | 3 | 2 | 1 | BRPCES16 |
| 17. Tuve episodios de llanto | 1 | 2 | 3 | 4 | BRPCES17 |

| | | Raramente O Ningún Tiempo (Menos que un día) | Alguna Tiempo (1-2 días) | Moderado Tiempo (3-4 días) | Siempre (5-7 días) | |
|-----|---|--|--------------------------------|----------------------------------|-----------------------|----------|
| 18. | Me sentí triste | 1 | 2 | 3 | 4 | BRPCES18 |
| 19. | Me sentí que no le gustaba a la gente | 1 | 2 | 3 | 4 | BRPCES19 |
| 20. | No pude animarme | 1 | 2 | 3 | 4 | BRPCES20 |
| 21. | Me sentí solitaria o apartada de los demás | 1 | 2 | 3 | 4 | BRPCES21 |

ESCALA DE ANSIEDAD ESTADO-RASGO (ESTADO MODIFICADO)
(STATE-TRAIT ANXIETY SCALE -- MODIFIED STATE)

Le voy a leer un número de declaraciones que han usado la gente para describirse. Al leerle cada declaración, por favor dígame la respuesta que describe como usted se siente en *este momento*.

| | De Ningún <u>Modo</u> | <u>Un poco</u> | <u>Moderadamente</u> | <u>Muchísimo</u> | |
|--|--------------------------|----------------|----------------------|------------------|---------|
| 1. Me siento calmada. ¿Diría usted que esto describe como se siente... | 1 | 2 | 3 | 4 | BRPST1 |
| 2. Me siento segura | 1 | 2 | 3 | 4 | BRPST2 |
| 3. Estoy tensa | 1 | 2 | 3 | 4 | BRPST3 |
| 4. Me siento forzada | 1 | 2 | 3 | 4 | BRPST4 |
| 5. Me siento tranquila | 1 | 2 | 3 | 4 | BRPST5 |
| 6. Me siento desconcertada | 1 | 2 | 3 | 4 | BRPST6 |
| 7. Actualmente estoy preocupada por posibles desgracias | 1 | 2 | 3 | 4 | BRPST7 |
| 8. Me siento satisfecha | 1 | 2 | 3 | 4 | BRPST8 |
| 9. Me siento asustada | 1 | 2 | 3 | 4 | BRPST9 |
| 10. Me siento cómoda | 1 | 2 | 3 | 4 | BRPST10 |
| 11. Me siento segura de mí misma | 1 | 2 | 3 | 4 | BRPST11 |
| 12. Me siento nerviosa | 1 | 2 | 3 | 4 | BRPST12 |
| 13. Me siento agitada | 1 | 2 | 3 | 4 | BRPST13 |
| 14. Me siento indecisa | 1 | 2 | 3 | 4 | BRPST14 |
| 15. Me siento relajada | 1 | 2 | 3 | 4 | BRPST15 |
| 16. Me siento contenta | 1 | 2 | 3 | 4 | BRPST16 |
| 17. Me siento preocupada | 1 | 2 | 3 | 4 | BRPST17 |
| 18. Me siento confundida | 1 | 2 | 3 | 4 | BRPST18 |
| 19. Me siento constante | 1 | 2 | 3 | 4 | BRPST19 |
| 20. Me siento agradable | 1 | 2 | 3 | 4 | BRPST20 |

GRACIAS POR SU COOPERACION.
(THANK YOU FOR YOUR COOPERATION).

¿Existe alguna otra cosa sobre la cuál desea comentar qué no hemos cubierto en esta entrevista?

HORA DE CONCLUSION:

____/____ a.m./p.m
hora minutos

BRPHR
BRPMN

INTERVIEWER REMARKS

- | | | |
|----|---|-------------------------------|
| 1. | Did respondent experience or exhibit emotional or psychological problems during the interview? | BRPR1 |
| | Yes 1 (ANSWER A) | |
| | No 2 | |
| A. | What was the problem? _____ _____ _____ | BRPR1A1 BRPR1A2 BRPR1A3 |
| 2. | Were there any other problems during the interview? | BRPR2 |
| | Yes 1 (ANSWER A) | |
| | No 2 | |
| A. | What was the problem? _____ _____ _____ | BRPR2A1 BRPR2A2 BRPR2A3 |
| 3. | Was interview conducted in English or Spanish? | BRPR3 |
| | English 1 (ANSWER A) | |
| | Spanish 2 | |
| A. | How much trouble does respondent have understanding English? | BRPR3A |
| | None 1 | |
| | Some 2 | |
| | A great deal 3 | |
| 4. | Regardless of whether or not interview was completed in one session, did the respondent <i>want to</i> terminate interview before interview was finished? | BRPR4 |
| | Yes 1 (ANSWER A) | |
| | No 2 | |
| A. | At what points and why? _____ _____ _____ | BRPR4A1 BRPR4A2 BRPR4A3 |
| 5. | Did respondent need to complete interview over two or more sessions? | BRPR5 |
| | Yes 1 (ANSWER A) | |
| | No 2 | |
| A. | Reasons given for needing to break up interview _____ _____ | BRPR5A1 BRPR5A2 |

6. Date interview started:

____/____/____
(mo) (da) (yr)

BRPR6MO
BRPR6DA
BRPR6YR

7. Date interview completed:

____/____/____
(mo) (da) (yr)

BRPR7MO
BRPR7DA
BRPR7YR

8. Number of interviewing sessions needed to complete interview:

One 1
Two 2
Three 3
Four 4

BRPR8

9. Name and ID of interviewer:

NAME

I.D.

BRPR9

10. Total time spent interviewing:

____/____
hours minutes

BRPR10

11. Proxy questionnaire was answered by:

Caregiving Daughter 1
Patient's Spouse 2
Other Daughter of Patient..... 3
Patient's Son..... 4
Other Relative (Specify _____)..... 5
NOT APPLICABLE; Patient completed
questionnaire herself 8

BRPR11

Interviewer Comments and observations not otherwise specified:

APPENDIX G

Daughter Questionnaire (English/Spanish)

CODED _____

ENTERED _____

VERIFIED _____

Time Started
_____ am/pm

Time Ended
_____ am/pm

**Aging Families and Breast Cancer:
Multigenerational Issues**

Daughter Interview

ID# _____

TIME BEGUN:

___ / ___ a.m./p.m.

SOCIODEMOGRAPHIC QUESTIONS

1. What is your date of birth?

___ / ___ / ___
month day year

BRDS1MO
BRDS1DA
BRDS1YR

2. What is the highest level of schooling you have completed?

Eighth grade or less1
Some High School.....2
High School Graduate or GED.....3
Some College4
Associate's Degree.....5
Technical or vocational school.....6
College Degree.....7
Some graduate school.....8
Graduate or professional degree.....9

BRDS2

3. How would you describe yourself? Would you say you are...

White1 (ASK A)
Black/African American.....2 (ASK A)
Asian or Pacific Islander3
American Indian/Alaskan native4
Other (SPECIFY _____)5 (ASK A)

BRDS3

- A. Are you of Hispanic origin or descent?

Yes.....1 (ASK B)
No.....2

BRDS3A

- B. Do you consider yourself to be...

Puerto Rican1
Dominican2
Cuban3
Mexican4
Ecuadorean5
Columbian6
Spanish or European.....7
Something else (SPECIFY: _____)10

BRDS3B

4. Are you currently employed, not employed, on disability, out on sick leave, or something else?

BRDS4

- Employed1 (ASK A)
Disability2 (ASK C)
Sick Leave3 (ASK C)
Not employed, laid off, looking for work.....4 (ASK B)
Retired5 (ASK C)
In school and not working6 (ASK B)
Keeping house7 (ASK B)
Other (SPECIFY _____).....8 (ASK B)

A. (IF EMPLOYED) About how many hours do you work in an average week?

BRDS4A

_____ # of hours IF LESSTHAN 35 HOURS GO TO D.
IF 35+ GO TO Q.5.

B. Have you ever held a job which lasted for six months or longer?

BRDS4B

Yes.....1
No.....2 (IF NO, GO TO Q. 8)

C. In what month and year did you last work?

BRDS4CMO
BRDS4CYR

_____/_____
month year

D. (IF WORKING PART-TIME OR NOT WORKING) Are you (working part-time/
not working) because of your mother's illness?

BRDS4D

Yes.....1
No.....2

5. What kind of work (do)(did) you do? That is, what (is)(was) your job called? (PROBE, IF
NECESSARY) What (do)(did) you actually do in that job? What (are) were some of your main duties
or responsibilities?

BRDS5

Occupation: _____

Job Title: _____

Duties: _____

A. What kind of company or industry is that? What do/did they do or make at the place where
you work(ed)?

6. Are/Were you self employed in your own business, practice, or working without pay in a family
business (on your main job)?

BRDS6

Yes, self employed1
No, work for someone else2

7. (What is/When you were working, what was) your annual salary before taxes from your job?
I'll start reading off a list of income ranges; just stop me when I reach the category that includes your income.

BRDS7

| | | |
|---------------------------|----|---------|
| \$5,000 or less..... | 1 | |
| \$5,001 - \$10,000..... | 2 | |
| \$10,001 - \$15,000..... | 3 | |
| \$15,001 - \$20,000..... | 4 | |
| \$20,001 - \$25,000..... | 5 | |
| | | |
| \$25,001 - \$30,000..... | 6 | |
| \$30,001 - \$40,000..... | 7 | |
| \$40,001 - \$50,000..... | 8 | |
| \$50,001 - \$60,000..... | 9 | |
| \$60,001 - \$70,000..... | 10 | |
| | | |
| \$70,001 - \$80,000..... | 11 | |
| \$80,001 - \$90,000..... | 12 | |
| \$90,001 - \$100,000..... | 13 | |
| \$100,001 or more | 14 | |
| | | |
| Does not know | 97 | (ASK A) |
| Refuses to answer | 99 | (ASK A) |

- A. Can you tell me if it was...

BRDS7A

| | |
|------------------------------------|---|
| Less than \$25,000 a year or | 1 |
| More than \$25,000 a year | 2 |
| DOESN'T KNOW; REFUSED | 3 |

8. What is your current marital status?

BRDS8

| | | |
|---|---|---------|
| Married | 1 | (ASK A) |
| IF VOLUNTEERED: Living with a partner | 2 | (ASK A) |
| Divorced | 3 | |
| Separated | 4 | |
| Widowed | 5 | |
| Never Married | 6 | |

- A. How long have you been (married/living together)?

BRDS8A

number of years

9. Do you have any children?

BRDS9

| | | |
|----------|---|---------|
| Yes..... | 1 | (ASK A) |
| No..... | 2 | |

- A. How many children do you have?

BRDS9A

number of children

10. Could you please tell me who lives with you in your household? **IF R. LIVES ALONE GO TO IN Q. 11. (ASK A-C FOR EACH PERSON IN HOUSEHOLD) (NOTE: IF HOUSEHOLD COMPOSITION HAS CHANGED FROM THE USUAL, CODE FOR COMPOSITION IN THE LAST MONTH), PROBE:** Anyone else?

| A. What is their relationship to you? | | B. Sex | | C. What was his/her age on his/her last birthday? |
|---------------------------------------|-------|--------|--------|---|
| | | Male | Female | |
| Pers. 1. | _____ | 1 | 2 | _____ |
| Pers. 2. | _____ | 1 | 2 | _____ |
| Pers. 3. | _____ | 1 | 2 | _____ |
| Pers. 4. | _____ | 1 | 2 | _____ |
| Pers. 5. | _____ | 1 | 2 | _____ |
| Pers. 6. | _____ | 1 | 2 | _____ |
| Pers. 7. | _____ | 1 | 2 | _____ |
| Pers. 8. | _____ | 1 | 2 | _____ |

BRDS10R1
BRDS10S1
BRDS10A1

BRDS10R2
BRDS10S2
BRDS10A2

BRDS10R3
BRDS10S3
BRDS10A3

BRDS10R4
BRDS10S4
BRDS10A4

BRDS10R5
BRDS10S5
BRDS10A5

BRDS10R6
BRDS10S6
BRDS10A6

BRDS10R7
BRDS10S7
BRDS10A7

BRDS10R8
BRDS10S8
BRDS10A8

11. So, including yourself, the total number of people living in your household is:

BRDS11

NEED FOR ASSISTANCE/TYPES OF CARE PROVIDED BY DAUGHTER

I'm going to read you a list of activities that your mother may be receiving some assistance with. As I read each activity please tell me if you or someone else is helping her with the activity. **(CIRCLE ALL THAT APPLY)**

| | Mother Does it <u>Herself</u> | Daughter Provides <u>Help</u> | Someone Provides <u>Help</u> | Not Done | Record relationship to the daughter |
|--|-------------------------------------|-------------------------------------|------------------------------------|-------------|--|
| 1. Light housekeeping such as dusting. Does your (mother) do this herself, do you help, does someone else help, or is this not done? | 1 | 2 | 3 (Who?_____) | 8 | BRDA1 BRDA1R1 BRDA1R2 |
| 2. Heavy housekeeping | 1 | 2 | 3 (Who?_____) | 8 | BRDA2 BRDA2R1 BRDA2R2 |
| 3. Cooking and meal preparation | 1 | 2 | 3 (Who?_____) | 8 | BRDA3 BRDA3R1 BRDA3R2 |
| 4. Shopping for clothes & household items | 1 | 2 | 3 (Who?_____) | 8 | BRDA4 BRDA4R1 BRDA4R2 |
| 5. Grocery shopping | 1 | 2 | 3 (Who?_____) | 8 | BRDA5 BRDA5R1 BRDA5R2 |
| 6. Bathing and showering | 1 | 2 | 3 (Who?_____) | 8 | BRDA6 BRDA6R1 BRDA6R2 |
| 7. Home health care tasks | 1 | 2 | 3 (Who?_____) | 8 | BRDA7 BRDA7R1 BRDA7R2 |
| 8. Getting dressed | 1 | 2 | 3 (Who?_____) | 8 | BRDA8 BRDA8R1 BRDA8R2 |
| 9. Using the toilet | 1 | 2 | 3 (Who?_____) | 8 | BRDA9 BRDA9R1 BRDA9R2 |
| 10. Getting in and out of a bed or chair | 1 | 2 | 3 (Who?_____) | 8 | BRDA10 BRDA10R1 BRDA10R2 |
| 11. Traveling to medical appointments | 1 | 2 | 3 (Who?_____) | 8 | BRDA11 BRDA11R1 BRDA11R2 |
| 12. Traveling for other purposes (work, visiting, or errands) | 1 | 2 | 3 (Who?_____) | 8 | BRDA12 BRDA12R1 BRDA12R2 |
| 13. Filling out forms (insurance claims, medical forms, applications for financial benefits) | 1 | 2 | 3 (Who?_____) | 8 | BRDA13 BRDA13R1 BRDA13R2 |

| | | <u>Mother Does it Herself</u> | <u>Daughter Provides Help</u> | <u>Someone Provides Help</u> | <u>Record relationship to the daughter</u> | <u>Not Done</u> | |
|-----|--|---------------------------------------|---------------------------------------|--------------------------------------|--|---------------------|--|
| 14. | Handling banking-related tasks | 1 | 2 | 3 (Who?_____) | 8 | | BRDA14 BRDA14R1 BRDA14R2 |
| 15. | Obtaining information about her illness or treatment | 1 | 2 | 3 (Who?_____) | 8 | | BRDA15 BRDA15R1 BRDA15R2 |
| 16. | Obtaining illness-related financial counseling or advice for (her/him) | 1 | 2 | 3 (Who?_____) | 8 | | BRDA16 BRDA16R1 BRDA16R2 |
| 17. | Obtaining illness-related legal counseling or advice for (her/him) | 1 | 2 | 3 (Who?_____) | 8 | | BRDA17 BRDA17R1 BRDA17R2 BRDA18 BRDA18R1 BRDA18R2 |
| 18. | Arranging for formal home or health care assistance | 1 | 2 | 3 (Who?_____) | 8 | | |

ILLNESS PREDICTABILITY

1. I usually know when my mother is going to have a good or bad day. Do you. . .

Strongly agree 5
Somewhat agree 4
Neither agree nor disagree 3
Somewhat disagree 2
Strongly disagree 1

BRDIP1

2. It is clear to me when my mother's illness is getting better or worse. Do you. . .

Strongly agree 5
Somewhat agree 4
Neither agree nor disagree 3
Somewhat disagree 2
Strongly disagree 1

BRDIP2

3. I can generally predict the course of my mother's illness. Do you. . .

Strongly agree 5
Somewhat agree 4
Neither agree nor disagree 3
Somewhat disagree 2
Strongly disagree 1

BRDIP3

4. My mother's physical distress is predictable. Do you. . .

Strongly agree 5
Somewhat agree 4
Neither agree nor disagree 3
Somewhat disagree 2
Strongly disagree 1

BRDIP4

APPRAISAL OF PERSONAL CONTROL OVER ILLNESS

- | | | |
|----|--|--------|
| 1. | How much personal control do you think you have over the amount of fatigue your mother experiences from day to day? Would you say you have . . . | BRDPC1 |
| | No control..... 5 | |
| | Very little control..... 4 | |
| | A moderate amount of control..... 3 | |
| | Quite a bit of control..... 2 | |
| | An extreme amount of control..... 1 | |
| | DOES NOT APPLY..... 8 | |
| 2. | How much personal control do you think you have over the amount of discomfort your mother experiences from day to day? Would you say you have. . . | BRDPC2 |
| | No control..... 5 | |
| | Very little control..... 4 | |
| | A moderate amount of control..... 3 | |
| | Quite a bit of control..... 2 | |
| | An extreme amount of control..... 1 | |
| | DOES NOT APPLY..... 8 | |
| 3. | How much personal control do you think you have over the amount of immobility your mother experiences from day to day? Would you say you have. . . | BRDPC3 |
| | No control..... 5 | |
| | Very little control..... 4 | |
| | A moderate amount of control..... 3 | |
| | Quite a bit of control..... 2 | |
| | An extreme amount of control..... 1 | |
| | DOES NOT APPLY..... 8 | |
| 4. | How much personal control do you think you have over the amount of pain your mother experiences from day to day? Would you say you have. . . | BRDPC4 |
| | No control..... 5 | |
| | Very little control..... 4 | |
| | A moderate amount of control..... 3 | |
| | Quite a bit of control..... 2 | |
| | An extreme amount of control..... 1 | |
| | DOES NOT APPLY..... 8 | |
| 5. | How much personal control do you believe you have over the long-term course of your mother's illness, (that is, whether it will improve or at least not worsen in the future)? Would you say you have. . . | BRDPC5 |
| | No control..... 5 | |
| | Very little control..... 4 | |
| | A moderate amount of control..... 3 | |
| | Quite a bit of control..... 2 | |
| | An extreme amount of control..... 1 | |
| | DOES NOT APPLY..... 8 | |
| 6. | How much personal control do you think you have over the medical care and treatment of your mother's illness? Would you say you have. . . | BRDPC6 |
| | No control..... 5 | |
| | Very little control..... 4 | |
| | A moderate amount of control..... 3 | |
| | Quite a bit of control..... 2 | |
| | An extreme amount of control..... 1 | |
| | DOES NOT APPLY..... 8 | |

FILIAL OBLIGATION

In this next series of questions, we will be asking you your opinions about help in the home

1. Married children should live close to parents to provide care. Do you. . .

| | |
|----------------------------------|---|
| Strongly agree | 5 |
| Somewhat agree | 4 |
| Neither agree nor disagree | 3 |
| Somewhat disagree | 2 |
| Strongly disagree | 1 |

BRDFO1

2. Children should not be expected to do tasks for their parents. . .

| | |
|----------------------------------|---|
| Strongly agree | 5 |
| Somewhat agree | 4 |
| Neither agree nor disagree | 3 |
| Somewhat disagree | 2 |
| Strongly disagree | 1 |

BRDFO2

3. Parents should expect adult children to assist them. . .

| | |
|----------------------------------|---|
| Strongly agree | 5 |
| Somewhat agree | 4 |
| Neither agree nor disagree | 3 |
| Somewhat disagree | 2 |
| Strongly disagree | 1 |

BRDFO3

4. It is a child's duty to assist parents. . .

| | |
|----------------------------------|---|
| Strongly agree | 5 |
| Somewhat agree | 4 |
| Neither agree nor disagree | 3 |
| Somewhat disagree | 2 |
| Strongly disagree | 1 |

BRDFO4

5. It is preferable to pay a professional for assistance with caregiving. . .

| | |
|----------------------------------|---|
| Strongly agree | 5 |
| Somewhat agree | 4 |
| Neither agree nor disagree | 3 |
| Somewhat disagree | 2 |
| Strongly disagree | 1 |

BRDFO5

6. Paying for professional help means a relative is not taking responsibility. . .

| | |
|----------------------------------|---|
| Strongly agree | 5 |
| Somewhat agree | 4 |
| Neither agree nor disagree | 3 |
| Somewhat disagree | 2 |
| Strongly disagree | 1 |

BRDFO6

7. It is better to give up a job to provide care than to pay a professional. . .

| | |
|----------------------------------|---|
| Strongly agree | 5 |
| Somewhat agree | 4 |
| Neither agree nor disagree | 3 |
| Somewhat disagree | 2 |
| Strongly disagree | 1 |

BRDFO7

CES-D SCALE

I will now read you a list of the ways you might have felt or behaved *during the past week*. As I read each statement, please tell me the category which best describes how often you have felt this way *during the past week*.

| | Rarely Or None Of The Time (Less Than <u>1 Day</u>) | Some Or A Little of The Time (1-2 Days) | Occasionally Or A Moderate Amount of Time (3-4 Days) | Most Or All Of The Time (5-7 Days) | |
|---|--|--|---|---|----------|
| <i>During the past week:</i> | | | | | |
| 1. I was bothered by things that usually don't bother me. Would you say you felt this way... | 1 | 2 | 3 | 4 | BRDCES1 |
| 2. I did not feel like eating; my appetite was poor | 1 | 2 | 3 | 4 | BRDCES2 |
| 3. I felt that I could not shake off the blues even with help from my friends or family | 1 | 2 | 3 | 4 | BRDCES3 |
| 4. I felt that I was just as good as other people | 4 | 3 | 2 | 1 | BRDCES4 |
| 5. I had trouble keeping my mind on what I was doing | 1 | 2 | 3 | 4 | BRDCES5 |
| 6. I felt depressed | 1 | 2 | 3 | 4 | BRDCES6 |
| 7. I felt that everything I did was an effort | 1 | 2 | 3 | 4 | BRDCES7 |
| 8. I felt hopeful about the future | 4 | 3 | 2 | 1 | BRDCES8 |
| 9. I thought my life had been a failure | 1 | 2 | 3 | 4 | BRDCES9 |
| 10. I felt fearful | 1 | 2 | 3 | 4 | BRDCES10 |
| 11. My sleep was restless | 1 | 2 | 3 | 4 | BRDCES11 |
| 12. I was happy | 4 | 3 | 2 | 1 | BRDCES12 |
| 13. I talked less than usual | 1 | 2 | 3 | 4 | BRDCES13 |
| 14. I felt lonely | 1 | 2 | 3 | 4 | BRDCES14 |
| 15. People were unfriendly | 1 | 2 | 3 | 4 | BRDCES15 |
| 16. I enjoyed life | 4 | 3 | 2 | 1 | BRDCES16 |
| 17. I had crying spells | 1 | 2 | 3 | 4 | BRDCES17 |

| | | Rarely Or None Of The Time (Less Than <u>1 Day</u>) | Some Or A Little of The Time (1-2 Days) | Occasionally Or A Moderate Amount of Time (3-4 Days) | Most Or All Of The Time (5-7 Days) | |
|-----|--|--|--|---|---|----------|
| 18. | I felt sad | 1 | 2 | 3 | 4 | BRDCES18 |
| 19. | I felt that people disliked me | 1 | 2 | 3 | 4 | BRDCES19 |
| 20. | I could not get "going" | 1 | 2 | 3 | 4 | BRDCES20 |
| 21. | I felt alone or cut off from other people | 1 | 2 | 3 | 4 | BRDCES21 |

STATE-TRAIT ANXIETY (MODIFIED - STATE ONLY)

I am going to read you a number of statements which people have used to describe themselves.

As I read each statement, please give me the answer which seems to describe how you feel *right now*.

| | | <u>Not at</u> <u>All</u> | <u>Somewhat</u> | <u>Moderately</u> <u>So</u> | <u>Very</u> <u>Much So</u> | |
|-----|--|-----------------------------|-----------------|--------------------------------|-------------------------------|---------|
| 1. | I feel calm. Would you say this describes how you feel. . . | 1 | 2 | 3 | 4 | BRDST1 |
| 2. | I feel secure | 1 | 2 | 3 | 4 | BRDST2 |
| 3. | I am tense | 1 | 2 | 3 | 4 | BRDST3 |
| 4. | I feel strained | 1 | 2 | 3 | 4 | BRDST4 |
| 5. | I feel at ease | 1 | 2 | 3 | 4 | BRDST5 |
| 6. | I feel upset | 1 | 2 | 3 | 4 | BRDST6 |
| 7. | I am presently worrying over possible misfortunes | 1 | 2 | 3 | 4 | BRDST7 |
| 8. | I feel satisfied | 1 | 2 | 3 | 4 | BRDST8 |
| 9. | I feel frightened | 1 | 2 | 3 | 4 | BRDST9 |
| 10. | I feel comfortable | 1 | 2 | 3 | 4 | BRDST10 |
| 11. | I feel self-confident | 1 | 2 | 3 | 4 | BRDST11 |
| 12. | I feel nervous | 1 | 2 | 3 | 4 | BRDST12 |
| 13. | I feel jittery | 1 | 2 | 3 | 4 | BRDST13 |
| 14. | I feel indecisive | 1 | 2 | 3 | 4 | BRDST14 |
| 15. | I feel relaxed | 1 | 2 | 3 | 4 | BRDST15 |
| 16. | I feel content | 1 | 2 | 3 | 4 | BRDST16 |
| 17. | I feel worried | 1 | 2 | 3 | 4 | BRDST17 |
| 18. | I feel confused | 1 | 2 | 3 | 4 | BRDST18 |
| 19. | I feel steady | 1 | 2 | 3 | 4 | BRDST19 |
| 20. | I feel pleasant | 1 | 2 | 3 | 4 | BRDST20 |

PHYSICAL BURDEN

1. Some people experience physical strain associated with caring for an ill person. *Since the diagnosis*, how much physical strain would you say you have experienced caring for your mother? Would you say. . .

| | | |
|-----------------------------------|---|--|
| A great deal of strain..... | 4 | |
| A moderate amount of strain | 3 | |
| A little strain or..... | 2 | |
| No strain | 1 | |

BRDPB1

2. *Since the diagnosis*, have you ever (been called/had to get up) during the night to take care of your mother?

| | | |
|----------|---|-------------|
| Yes..... | 1 | (ASK A & B) |
| No | 2 | |

BRDPB2

- A. How many times has that happened *since the diagnosis*?

of times

BRDPB2A

- B. (ASK IF R. LIVES WITH PATIENT) On those nights when you had to get up to take care of your mother, how many times did you usually get up?

| | | |
|----------------------|---|--|
| One time | 1 | |
| 2 times | 2 | |
| 3-4 times..... | 3 | |
| 5 times or more..... | 4 | |

BRDPB2B

3. To what extent has caring for your mother affected your energy for your regular .. daily activities? Would you say that you have. . .

| | | |
|---------------------------------------|---|--|
| As much energy as you had before..... | 4 | |
| A little less energy | 3 | |
| Somewhat less energy, or | 2 | |
| A lot less energy | 1 | |

BRDPB3

TIME BURDEN

1. As a result of your caregiving *since your mother's diagnosis*. . .

| | <u>YES</u> | <u>NO</u> | |
|---|------------|-----------|---------|
| a. Have you cut down the <i>amount of time</i> you spent doing your regular daily activities? | 1 | 2 | BRDTB1A |
| b. <i>Accomplished less</i> than you would like | 1 | 2 | BRDTB1B |
| c. Don't do your regular daily activities as <i>carefully</i> as usual | 1 | 2 | BRDTB1C |

SOCIAL BURDEN

1. How frequently do you feel as though you don't have enough time to take care of your own household duties and tasks? Would you say...

| | | |
|-----------------|---|--|
| Often | 4 | |
| Sometimes | 3 | |
| Rarely | 2 | |
| Never | 1 | |

BRDSB1

2. *Since your mother's diagnosis*, to what extent has your mother's illness made it difficult for you to establish a daily routine and plan activities? Would you say. . .

| | | |
|--------------------|---|--|
| Not at all..... | 1 | |
| Only a little..... | 2 | |
| Somewhat..... | 3 | |
| A great deal | 4 | |

BRDSB2

3. *Since your mother's diagnosis*, to what extent has your mother's illness made you reduce the amount of time you spend with other family members? Would you say. . .

| | | |
|--------------------|---|--|
| Not at all..... | 1 | |
| Only a little..... | 2 | |
| Somewhat..... | 3 | |
| A great deal | 4 | |

BRDSB3

4. *Since your mother's diagnosis*, to what extent has your mother's illness made you reduce the amount of time you spend with friends, neighbors, and acquaintances? Would you say. . .

| | | |
|---|---|---|
| Not at all..... | 1 | |
| Only a little..... | 2 | |
| Somewhat..... | 3 | |
| A great deal | 4 | |
| IF VOLUNTEERED: Never did this | | 8 |

BRDSB4

5. *Since your mother's diagnosis*, to what extent has your mother's illness, made you reduce outside activities, such as going on vacation or having a hobby?

| | | |
|---|---|---|
| Not at all..... | 1 | |
| Only a little..... | 2 | |
| Somewhat..... | 3 | |
| A great deal | 4 | |
| IF VOLUNTEERED: Never did this | | 8 |

BRDSB5

EMPLOYMENT BURDEN

IF R. IS NOT CURRENTLY EMPLOYED, GO TO NEXT SECTION – “FINANCIAL BURDEN”

EVERYONE ELSE, ASK:

- | | | |
|----|--|--------|
| 1. | <p><i>Since your mother's diagnosis</i>, on how many days would you say you have come in to work late or left early because your mother felt sick and you could not leave him/her alone, or because you had to escort him/her to the hospital or medical appointment, or because you had to run errands for him/her?</p> <p>_____ # of days</p> | BRDEB1 |
| 2. | <p><i>Since your mother's diagnosis</i>, how many days have you taken off from work as “sick” days, vacation days or personal days due to you mother's illness, such as when she felt sick and could not be left alone, or you had to escort him/her to the hospital or to a medical appointment, or had to run errands for him/her?</p> <p>_____ # of days</p> | BRDEB2 |
| 3. | <p>IF ANY DAYS, ASK: How many of these days off from work did you have to take without pay?</p> <p>_____ # of days</p> | BRDEB3 |
| 4. | <p><i>Since your mother's diagnosis</i>, to what extent has your caregiving affected your ability to concentrate on the job, or in any other ways affected your ability to put in a good day's work? Would you say...</p> <p>To a great extent4</p> <p>To some extent3</p> <p>To a small extent2</p> <p>Not at all1</p> <p>IF VOLUNTEERED: Does not apply, self-employed, freelance8</p> | BRDEB4 |
| 5. | <p><i>Since your mother's diagnosis</i>, to what extent has your caregiving created problems for you with your supervisor or co-workers because of missed time from work or poor work performance? Would you say...</p> <p>To a great extent4</p> <p>To some extent3</p> <p>To a small extent2</p> <p>Not at all1</p> <p>IF VOLUNTEERED: Does not apply, self-employed, freelance8</p> | BRDEB5 |

FINANCIAL BURDEN

- | | | |
|----|--|---------|
| 1. | <p><i>Since your mother's diagnosis</i>, to what extent has your mother's illness caused you to pass up opportunities to improve your financial situation, such as turning down a promotion, not seeking additional sources of income, or passing up job opportunities? Would you say . . .</p> <p style="margin-left: 40px;">To a great extent4</p> <p style="margin-left: 40px;">To some extent3</p> <p style="margin-left: 40px;">To a small extent2</p> <p style="margin-left: 40px;">Not at all1</p> | BRDFB1 |
| 2. | <p>Some people find that taking care of someone that is ill can <i>financially</i> affect their usual habits and lifestyle. How much has taking care of your mother changed <i>your financial</i> habits and lifestyle <i>since your mother's diagnosis</i>? Would you say it has made . . .</p> <p style="margin-left: 40px;">Many changes in your usual ways of living4</p> <p style="margin-left: 40px;">Some changes3</p> <p style="margin-left: 40px;">A few changes2</p> <p style="margin-left: 40px;">No changes at all1</p> | BRDFB2 |
| 3. | <p>Illness can often cause financial problems. How serious are your financial problems due to your mother's illness <i>since the diagnosis</i>? Would you say . . .</p> <p style="margin-left: 40px;">Very serious.....4</p> <p style="margin-left: 40px;">Somewhat serious.....3</p> <p style="margin-left: 40px;">Not very serious.....2</p> <p style="margin-left: 40px;">No financial problems at all.....1</p> | BRDFB3 |
| 4. | <p><i>Since your mother's diagnosis</i>, have you had any extra expenses because you have been caring for your mother that you would not have had otherwise, such as paying for special food or household items for (her/him), or extra transportation or telephone costs?</p> <p style="margin-left: 40px;">Yes.....1 (ASK A)</p> <p style="margin-left: 40px;">No2</p> | BRDFB4 |
| A | <p><i>Since the diagnosis</i>, approximately how much money have you spent on these extra expenses? Would you say . . .</p> <p style="margin-left: 40px;">Less than \$501</p> <p style="margin-left: 40px;">\$51 - \$1002</p> <p style="margin-left: 40px;">\$101 - \$2003</p> <p style="margin-left: 40px;">\$201 - \$5004</p> <p style="margin-left: 40px;">\$501 - \$1,0005</p> <p style="margin-left: 40px;">More than \$1,0006</p> | BRDFB4A |
| 5. | <p>(Apart from these out-of-pocket expenses), do you provide any financial support to your mother to help with illness-related expenses?</p> <p style="margin-left: 40px;">Yes.....1 (ASK A-C)</p> <p style="margin-left: 40px;">No2</p> | BRDFB5 |

A. *Since the diagnosis*, have you had to, as a result of your mother's illness. . .

YES NO

Use savings 1 2 BRDFB5A1

Sell assets like stocks or bonds, your home, a car, major
appliances, investment property, or other real estate

(SPECIFY) 1 2 BRDFB5A2

Borrow money? 1 2 BRDFB5A3

B. Approximately how much money have you spent on your mother's illness-related
expenses to date, including savings, or other assets *since the diagnosis*? I am going to read to
you some figures; just stop me when I reach the category that includes the amount you have spent.

BRDFB5B

Less than \$1,0001
\$ 1,000 - \$3,0002
\$ 3,001 - \$5,0003
\$ 5,001 - \$10,0004
\$10,001 - \$15,0005
\$15,001 - \$20,0006
\$20,001+7

C. Would you say that the money you contribute has been. . .

BRDFB5C

A great financial hardship3
Somewhat of a hardship2
Not a hardship1

6. *Since the diagnosis*, has your mother had any paid helpers, such as a
nurse, housekeeper, or health aide who were hired to help her due to her illness?

BRDFB6

Yes1 (ASK A)
No2

A. Do you help pay for this paid help?

BRDFB6A

Yes1
No2

7. Has anyone else, such as other family members or friends, helped to pay for any of
your mother's illness-related costs *since the diagnosis*?

BRDFB7

Yes1 (ASK A)
No2

A. Who has helped financially? Please tell me their relationship to you? (PROBE: ANYONE ELSE?)

| <u>Relationship to Caregiving Daughter</u> | <u>Sex</u> | |
|--|-------------|---------------|
| | <u>Male</u> | <u>Female</u> |
| _____ | 1 | 2 |
| _____ | 1 | 2 |
| _____ | 1 | 2 |

BRDF7AR1
BRDF7AS1
BRDF7AR2
BRDF7AS2
BRDF7AR3
BRDF7AS3

NETWORK OF RELATIONSHIPS (Abbreviated)

We are interested in how illness changes relationships. In this next series of items we ask about how your relationship with your mother has been *since her diagnosis* and how it was *prior to her illness*

| | <u>Not at all or a little</u> | <u>Somewhat</u> | <u>Very</u> | <u>Extremely</u> | <u>The most</u> | <u>DNA</u> | |
|---|-----------------------------------|-----------------|-------------|------------------|---------------------|------------|---------|
| 1. How much do you and your mother get upset or mad at each other? | | | | | | | |
| a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR1A |
| b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR1B |
| 2. How satisfied are you with your relationship with your mother? | | | | | | | |
| a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR2A |
| b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR2B |
| 3. How much do you tell your mother everything? | | | | | | | |
| a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR3A |
| b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR3B |
| 4. How much do you help your mother with things she can't do by herself? | | | | | | | |
| a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR4A |
| b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR4B |
| 5. How much does your mother treat you like you're admired and respected? | | | | | | | |
| a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR5A |
| b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR5B |
| 6. How much do you and your mother disagree and quarrel? | | | | | | | |
| a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR6A |
| b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR6B |

| | | <u>Not at all or a little</u> | <u>Somewhat</u> | <u>Very</u> | <u>Extremely</u> | <u>The most</u> | <u>DNA</u> | |
|-----|--|-----------------------------------|-----------------|-------------|------------------|---------------------|------------|----------|
| 7. | How happy are you with the way things are between you and your mother? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR7A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR7B |
| 8. | How much do you share your secrets and private feelings with your mother? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR8A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR8B |
| 9. | How much do you protect and look out for your mother? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR9A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR9B |
| 10. | How much does your mother treat you like you're good at many things? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR10A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR10B |
| 11. | How much do you and your mother argue with each other? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR11A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR11B |
| 12. | How good is your relationship with your mother? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR12A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR12B |
| 13. | How much do you talk to your mother about things that you don't want others to know? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR13A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR13B |

| | | <u>Not at all or a little</u> | <u>Somewhat</u> | <u>Very</u> | <u>Extremely</u> | <u>The most</u> | <u>DNA</u> | |
|-----|---|--|------------------------------|---------------------------|-------------------------|-------------------------------------|------------|----------|
| 14. | How much do you take care of your mother? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR14A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR14B |
| 15. | How much does your mother like or approve of the things you do? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR15A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR15B |
| 16. | How close is your relationship with your mother | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR16A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR16B |
| | | <u>Mother almost always does</u> | <u>Mother often does</u> | <u>About the same</u> | <u>You often do</u> | <u>You almost always do</u> | <u>DNA</u> | |
| 17. | Who tells the other person what to do more often, you or your mother? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR17A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR17B |
| 18. | Between you and your mother who tends to be the BOSS in this relationship? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR18A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR18B |
| 19. | In your relationship with your mother who tends to take charge and decide what should be done? | | | | | | | |
| | a. since the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR19A |
| | b. prior to the diagnosis | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR19B |

IMPACT OF EVENT SCALE

Some time ago your mother was diagnosed with breast cancer. I will now read you a list of comments made by people facing similar kinds of stressful life events. As I read each statement, think about your mother's illness and your experiences since her diagnosis and please tell me how often *during the past week* each comment was true for you.

| <i>During the past week:</i> | <u>Not at all</u> | <u>Rarely</u> | <u>Sometimes</u> | <u>Often</u> | |
|---|-------------------|---------------|------------------|--------------|----------|
| 1. I thought about it when I didn't mean to. Would you say you this was true for you . . . | 1 | 2 | 3 | 4 | BRDIES1 |
| 2. I avoided letting myself get upset when I thought about it or was reminded of it. | 1 | 2 | 3 | 4 | BRDIES2 |
| 3. I tried to remove it from my memory. | 1 | 2 | 3 | 4 | BRDIES3 |
| 4. I had trouble falling asleep or staying asleep because of pictures or thoughts about it that came into mind. | 1 | 2 | 3 | 4 | BRDIES4 |
| 5. I had waves of strong feelings about it. | 1 | 2 | 3 | 4 | BRDIES5 |
| 6. I had dreams about it. | 1 | 2 | 3 | 4 | BRDIES6 |
| 7. I stayed away from reminders of it. | 1 | 2 | 3 | 4 | BRDIES7 |
| 8. I felt as if it hadn't happened or it wasn't real | 1 | 2 | 3 | 4 | BRDIES8 |
| 9. I tried not to talk about it. | 1 | 2 | 3 | 4 | BRDIES9 |
| 10. Pictures about it popped into my mind. | 1 | 2 | 3 | 4 | BRDIES10 |
| 11. Other things kept making me think about it. | 1 | 2 | 3 | 4 | BRDIES11 |
| 12. I was aware that I still had a lot of feelings about it, but I didn't deal with them. | 1 | 2 | 3 | 4 | BRDIES12 |
| 13. I tried not to think about it. | 1 | 2 | 3 | 4 | BRDIES13 |
| 14. Any reminder brought back feelings about it. | 1 | 2 | 3 | 4 | BRDIES14 |
| 15. My feelings about it were kind of numb. | 1 | 2 | 3 | 4 | BRDIES15 |

PERCEIVED RISK OF BREAST CANCER

1. In your opinion, compared to other women your age, what are your chances of getting breast cancer?
Would you say . . .

BRDPR1

Much lower.....1
Somewhat lower2
The same3
Somewhat higher.....4
Much higher5

2. How has your mother's diagnosis of breast cancer affected your perception of your own chances of
developing breast cancer? Would you say, it has . . .

BRDPR2

Had no effect on me1
Made me feel somewhat more at risk2
Made me feel a lot more at risk3

3. Compared to other women *with* a mother with breast cancer, what are your chances of developing
breast cancer? Would you say . . .

BRDPR3

Much lower.....1
Somewhat lower2
The same3
Somewhat higher4
Much higher5

4. Compared to other women *without* a mother with breast cancer, what are your chances of
developing breast cancer? Would you say . . .

BRDPR4

Much lower.....1
Somewhat lower2
The same3
Somewhat higher4
Much higher5

BREAST CANCER QUESTIONNAIRE

- | | | |
|-----|---|----------|
| 1. | What is your height? _____ feet _____ inches | BRDCQ1 |
| 2. | What is your weight? _____ pounds | BRDCQ2 |
| 3. | Do you eat 3 or more servings of vegetables a day? <i>(1 serving is about 1 cup of raw leafy greens or 2 cup of other vegetables, raw or cooked.)</i> Yes1 No.....2 | BRDCQ3 |
| 4. | Do you usually drink 1 or more servings of alcohol a day? <i>(1 serving is a can of beer, a glass of wine, or a shot of hard liquor.)</i> Yes1 No.....2 | BRDCQ4 |
| 5. | How old were you when you started your period? Younger than 151 15 or older2 | BRDCQ5 |
| 6. | Are you currently taking a birth control pill? Yes1 No.....2 | BRDCQ6 |
| 7. | How many children have you given birth to? None1 One2 Two or more3 | BRDCQ7 |
| 8. | How old were you when you first gave birth? Under 351 35 or older2 | BRDCQ8 |
| 9. | Have you breast-fed for a total of at least 1 year? Yes1 No.....2 | BRDCQ9 |
| 10. | Are you menopausal? Yes1 No.....2 | BRDCQ10 |
| | (ASK A-C) | |
| A. | Did you become menopausal before the age of 55? Yes1 No.....2 | BRDCQ10A |

- B. Are you currently on hormone replacement therapy? BRDCQ10B
 Yes1
 No.....2
- C. Have you ever been on hormone replacement therapy? BRDCQ10C
 Yes1
 No.....2
11. Have you ever had benign breast disease? BRDCQ11
 Yes1
 No.....2
12. Have you ever had a breast biopsy? BRDCQ12
 Yes1 (ASK A-B)
 No.....2
- A. How many breast biopsies have you had? BRDCQ12A
 _____ (Number)
- B. At what age was your first biopsy? BRDCQ12B
 _____ (Age)
13. Do you have any sisters who have ever had breast cancer? BRDCQ13
 Yes1 (ASK A)
 No.....2
- A. How many of your sisters have had breast cancer? BRDCQ13A
 _____ (Number)
14. Is your ethnicity mostly Jewish? BRDCQ14
 Yes1
 No.....2
15. Do you conduct monthly breast self-examinations? BRDCQ15
 Yes1
 No.....2
16. Do you have regular mammograms? BRDCQ16
 Yes1
 No.....2
17. Approximately how many months ago did you have your last mammogram? BRDCQ17
 _____(Months)

Thank you for your cooperation. Is there anything else you'd like to comment on that we have not covered in this interview?

TIME ENDED:

____/____ a.m./p.m
hour minutes

BRDHR
BRDMN

INTERVIEWER REMARKS

1. Did respondent experience or exhibit emotional or psychological problems during the interview?

BRDR1

Yes 1 (ANSWER A)
No 2

- A. What was the problem? _____

BRDR1A1
BRDR1A2
BRDR1A3

2. Were there any other problems during the interview?

BRDR2

Yes 1 (ANSWER A)
No 2

- A. What was the problem? _____

BRDR2A1

BRDR2A2

BRDR2A3

3. Was interview conducted in English or Spanish?

BRDR3

English 1 (ANSWER A)
Spanish 2

- A. How much trouble does respondent have understanding English?

BRDR3A

None 1
Some 2
A great deal 3

4. Regardless of whether or not interview was completed in one session, did the respondent *want to* terminate interview before interview was finished?

BRDR4

Yes 1 (ANSWER A)
No 2

- A. At what points and why?

BRDR4A1
BRDR4A2
BRDR4A3

5. Did respondent need to complete interview over two or more sessions?

BRDR5

Yes 1 (ANSWER A)
No 2

- A. Reasons given for needing to break up interview _____

BRDR5A1

BRDR5A2

6. Date interview started:

____/____/____
(mo) (da) (yr)

BRDR6MO
BRDR6DA
BRDR6YR

7. Date interview completed:

____/____/____
(mo) (da) (yr)

BRDR7MO
BRDR7DA
BRDR7YR

8. Number of interviewing sessions needed to complete interview:

One 1
Two 2
Three 3
Four 4

BRDR8

9. Name and ID of interviewer:

NAME

I.D.

BRDR9

10. Total time spent interviewing:

____/____
hours minutes

BRDR10

Interviewer Comments and observations not otherwise specified:

CODED _____

ENTERED _____

VERIFIED _____

Time Started
_____ am/pm

Time Ended
_____ am/pm

**Aging Families and Breast Cancer:
Multigenerational Issues**

Entrevista Con La Hija

**Numero De Identificación Del Paciente:
(Patient ID #)**

TIME BEGUN:

____ / ____ a.m./p.m.

DATOS DE ANTECEDENTES
(BACKGROUND QUESTIONS)

1. ¿Cuál es su fecha de nacimiento?

____ / ____ / ____
(mes) (día) (año)

BRDS1MO
BRDS1DA
BRDS1YR

2. ¿Cuál es el grado más alto de instrucción escolar que usted ha completado?

BRDS2

Octavo grado o menos1
Algunos años de escuela superior2
Graduado de escuela superior o recipiente de diploma de equivalencia
general (GED)3
Algunos años de colegio4
Grado asociado5
Escuela vocacional o técnico6
Grado universitario (bachillerato)7
Algunos años de escuela graduada8
Diploma licenciado o profesional9

3. ¿Cómo se describe usted? ¿Diría usted que es...

BRDS3

Blanco1 (PREGUNTE A)
Negro o Afroamericano2 (PREGUNTE A)
Asiático o Isleopacífico3
De raza indígena-americano o alasqueño4
Otra (ESPECIFIQUE)5 (PREGUNTE A)

- A. ¿Es usted de descendencia Hispánica?

BRDS3A

Sí1 (PREGUNTE B)
No2

- B. ¿Se considera usted...

BRDS3B

Puertorriqueño1
Dominicano2
Cubano3
Mejicano4
Ecuatoriano5
Colombiano6
Español o europeo7
De otra nacionalidad (ESPECIFIQUE)10

4. Actualmente, ¿está usted empleado, desempleado, recibiendo beneficios por incapacidad, fuera de su trabajo por enfermedad u otra cosa?

BRDS4

- | | | |
|---|---|--------------|
| Empleado..... | 1 | (PREGUNTE A) |
| Recibiendo beneficios por incapacidad..... | 2 | (PREGUNTE C) |
| Afuera de su trabajo por enfermedad..... | 3 | (PREGUNTE C) |
| Desempleado, despedido o buscando trabajo | 4 | (PREGUNTE B) |
| Jubilado | 5 | (PREGUNTE C) |
| Estudiando y <u>no</u> trabajando..... | 6 | (PREGUNTE B) |
| Ama de casa..... | 7 | (PREGUNTE B) |
| Otra (ESPECIFIQUE)..... | 8 | (PREGUNTE B) |

A. (SI EMPLEADO): ¿Cuántas horas trabaja por semana?

BRDS4A

_____ núm. de horas (Si menos de 35 horas, pase a la D. Si 35 o más, pase a la Preg. 5.)

B. ¿Ha tenido alguna vez un trabajo que durara seis meses o más?

BRDS4B

| | | |
|----------|---|----------------------|
| Sí | 1 | |
| No | 2 | (Pase a la Preg. 8.) |

C. ¿En qué mes y año trabajo usted por última vez?

BRDS4CMO
BRDS4CYR

_____/_____
(mes) (año)

D. (SI TRABAJA TIEMPO PARCIAL O NO TRABAJA): (¿Trabaja usted tiempo parcial o no trabaja) debido a su enfermedad?

BRDS4D

| | |
|----------|---|
| Sí | 1 |
| No | 2 |

5. ¿Qué tipo de trabajo (hace/hizo) usted? Es decir, ¿qué título (tiene/tenía) en su trabajo? (INDAGUE SI ES NECESARIO.) ¿Qué (hace/hacía) en su trabajo? ¿Cuáles (son/fueron) sus responsabilidades principales?

BRDS5

Ocupación: _____

Título: _____

Responsabilidades: _____

A. ¿Qué clase de compañía o industria es esa? ¿Qué hacen en el lugar dónde usted (trabaja/trabajó)?

6. ¿Es/fue usted empleado en su propio negocio o práctica, o trabaja/trabajó sin sueldo en un negocio familiar (en su trabajo principal)?

BRDS6

| | |
|--|---|
| Sí, empleado por si misma..... | 1 |
| No, trabaja/trabajó para otra persona..... | 2 |

7. ¿Cuál fue o cuál es su salario bruto anual? Le voy a leer una lista de cantidades de ingreso. Le pido que me indique cuando me acerque a la categoría que incluya su ingreso.

BRDS7

| | |
|----------------------------|----|
| \$5,000 o menos..... | 1 |
| \$5,001 a \$10,000 | 2 |
| \$10,001 a \$15,000 | 3 |
| \$15,001 a \$20,000 | 4 |
| \$20,001 a \$25,000 | 5 |
| \$25,001 a \$30,000 | 6 |
| \$30,001 a \$40,000 | 7 |
| \$40,001 a \$50,000 | 8 |
| \$50,001 a \$60,000 | 9 |
| \$60,001 a \$70,000 | 10 |
| \$70,001 a \$80,000 | 11 |
| \$80,001 a \$90,000 | 12 |
| \$90,001 a \$100,000 | 13 |
| \$100,001 o más..... | 14 |

| | | |
|------------------------|----|--------------|
| No sabe..... | 97 | (PREGUNTE A) |
| Rehusa responder | 99 | (PREGUNTE A) |

- A. ¿Me puede decir si fue...

BRDS7A

| | |
|----------------------------------|---|
| Menos de \$25,000 al año, o..... | 1 |
| Más de \$25,000 al año? | 2 |
| NO SABE; REHUSO | 3 |

8. ¿Cuál es su estado civil?

BRDS8

| | | |
|--|---|--------------|
| Casada | 1 | (PREGUNTE A) |
| (SI EXPRESADO POR EL ENTREVISTADO): | | |
| Viviendo con su pareja | 2 | (PREGUNTE A) |
| Divorciada | 3 | |
| Separada | 4 | |
| Enviudada..... | 5 | |
| Soltera/Nunca casada | 6 | |

- A. ¿Cuánto tiempo hace que está casada/viviendo con su pareja?

BRDS8A

núm. de años

9. ¿Tiene usted algunos hijos?

BRDS9

| | | |
|----------|---|--------------|
| Sí | 1 | (PREGUNTE A) |
| No | 2 | |

- A. ¿Cuántos hijos tiene usted?

BRDS9A

núm. de hijos

10. Me puede decir, por favor, ¿quién vive con usted en su hogar? (PREGUNTE DEL A AL C PARA CADA PERSONA EN EL HOGAR.) (SI HA CAMBIADO LA COMPOSICION DEL HOGAR DE LO USUAL, CODIFIQUE DE ACUERDO A LA COMPOSICION EN EL ÚLTIMO MES.) INDAGUE: ¿Alguien más?

| A. ¿Cuál es el parentesco entre usted y ... | B. Sexo | | C. ¿Qué edad tiene? | |
|---|---------|--------|---------------------|----------------------------------|
| | Varón | Hembra | | |
| Persona 1 <u> </u> | 1 | 2 | <u> </u> | BRDS10R1 BRDS10S1 BRDS10A1 |
| Persona 2 <u> </u> | 1 | 2 | <u> </u> | BRDS10R2 BRDS10S2 BRDS10A2 |
| Persona 3 <u> </u> | 1 | 2 | <u> </u> | BRDS10R3 BRDS10S3 BRDS10A3 |
| Persona 4 <u> </u> | 1 | 2 | <u> </u> | BRDS10R4 BRDS10S4 BRDS10A4 |
| Persona 5 <u> </u> | 1 | 2 | <u> </u> | BRDS10R5 BRDS10S5 BRDS10A5 |
| Persona 6 <u> </u> | 1 | 2 | <u> </u> | BRDS10R6 BRDS10S6 BRDS10A6 |
| Persona 7 <u> </u> | 1 | 2 | <u> </u> | BRDS10R7 BRDS10S7 BRDS10A7 |
| Persona 8 <u> </u> | 1 | 2 | <u> </u> | BRDS10R8 BRDS10S8 BRDS10A8 |

11. Incluyéndose a usted, el número total de personas que viven en su hogar es:

BRDS11

NECESIDAD DE AYUDA
(NEED FOR ASSISTANCE/TYPES OF CARE PROVIDED BY DAUGHTER)

Le voy a leer una lista de actividades con las cuales su madre está recibiendo ayuda. Al leerle cada actividad, por favor dígame si usted u otra persona le está ayudando al paciente llevar a cabo la actividad.

| | Madre lo hace <u>por sí misma</u> | La hija <u>ayuda</u> | Otra person provee <u>ayuda</u> | <u>No</u> <u>se hace</u> | |
|---|---|-------------------------|---------------------------------------|-----------------------------|--|
| | | | | | (Detalle el parentesco con la hija) |
| 1. Limpieza leve (tal como sacar el polvo). ¿Hace su madre esto por sí misma, le ayuda usted, le ayuda otra persona o no se hace esto? | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA1 BRDA1R1 BRDA1R2 |
| 2. Hacer la limpieza pesada de la casa | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA2 BRDA2R1 BRDA2R2 |
| 3. Planificar y cocinar las comidas | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA3 BRDA3R1 BRDA3R2 |
| 4. Hacer la compra de ropa y de artículos para el hogar | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA4 BRDA4R1 BRDA4R2 |
| 5. Hacer la compra de comestibles | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA5 BRDA5R1 BRDA5R2 |
| 6. Bañarse | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA6 BRDA6R1 BRDA6R2 |
| 7. Hacer tareas relacionadas con el cuidado de la salud en la casa (tales como mantenerse al tanto de sus medicamentos recetados o cambiárselos vendajes) | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA7 BRDA7R1 BRDA7R2 |
| 8. Vestirse | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA8 BRDA8R1 BRDA8R2 |
| 9. Utilizar el inodoro | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA9 BRDA9R1 BRDA9R2 |
| 10. Levantarse de la cama o de una silla | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA10 BRDA10R1 BRDA10R2 |
| 11. Viajar a sus citas médicas | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA11 BRDA11R1 BRDA11R2 |
| 12. Viajar con otros propósitos (tales como para trabajar, visitar o para hacer mandados) | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA12 BRDA12R1 BRDA12R2 |
| 13. Llenar formularios (tales como reclamos de seguro, formularios médicos o solicitudes para beneficios financieros) | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA13 BRDA13R1 BRDA13R2 |

(Detalle el parentesco
con la hija)

| | | | | | |
|--|---|---|-------------------|---|--------------------------------|
| 14. Manejar las tareas bancarias | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA14 BRDA14R1 BRDA14R2 |
| 15. Obtener información sobre su enfermedad o tratamiento | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA15 BRDA15R1 BRDA15R2 |
| 16. Obtener consejería financiera relacionada a su enfermedad | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA16 BRDA16R1 BRDA16R2 |
| 17. Obtener consejería legal relacionada a su enfermedad | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA17 BRDA17R1 BRDA17R2 |
| 18. Hacer arreglos para el cuidado de salud formal en el hogar | 1 | 2 | 3 (¿Quién? _____) | 8 | BRDA18 BRDA18R1 BRDA18R2 |

PRONOSTICABILIDAD DE LA ENFERMEDAD
(ILLNESS PREDICTABILITY)

- | | | |
|----|--|--------|
| 1. | Generalmente, conozco cuando mi madre va a tener un buen día o un mal día. ¿Está usted... Fuertemente de acuerdo 5 Un poco de acuerdo 4 Ni de acuerdo ni en desacuerdo 3 Un poco en desacuerdo 2 Fuertemente en desacuerdo 1 | BRDIP1 |
| 2. | Es evidente para mí cuando la enfermedad de mi madre está mejorándose o empeorándose. ¿Está usted... Fuertemente de acuerdo 5 Un poco de acuerdo 4 Ni de acuerdo ni en desacuerdo 3 Un poco en desacuerdo 2 Fuertemente en desacuerdo 1 | BRDIP2 |
| 3. | Generalmente, puedo predecir el curso de la enfermedad de mi madre. ¿Está usted... Fuertemente de acuerdo 5 Un poco de acuerdo 4 Ni de acuerdo ni en desacuerdo 3 Un poco en desacuerdo 2 Fuertemente en desacuerdo 1 | BRDIP3 |
| 4. | La angustia física de mi madre es pronosticable. ¿Está usted... Fuertemente de acuerdo 5 Un poco de acuerdo 4 Ni de acuerdo ni en desacuerdo 3 Un poco en desacuerdo 2 Fuertemente en desacuerdo 1 | BRDIP4 |

CONTROL SOBRE LA ENFERMEDAD/(ILLNESS CONTROL)

- | | | |
|----|--|--------|
| 1. | ¿Cuánto control personal piensa usted que tiene sobre la cantidad de cansancio que experimenta de día a día? ¿Diría que tiene... | BRDIC1 |
| | Ningún control 5 Muy poco control..... 4 Una cantidad moderada de control 3 Bastante control 2 Extremo control 1 NO APLICA 8 | |
| 2. | ¿Cuánto control personal piensa usted que tiene sobre la cantidad de incomodidad qué experimenta de día a día? ¿Diría que tiene... | BRDIC2 |
| | Ningún control 5 Muy poco control..... 4 Una cantidad moderada de control 3 Bastante control 2 Extremo control 1 NO APLICA 8 | |
| 3. | ¿Cuánto control personal piensa usted que tiene sobre la cantidad de inmovilidad que experimenta de día a día? ¿Diría que tiene... | BRDIC3 |
| | Ningún control 5 Muy poco control..... 4 Una cantidad moderada de control 3 Bastante control 2 Extremo control 1 NO APLICA 8 | |
| 4. | ¿Cuánto control personal piensa usted que tiene sobre la cantidad de dolor qué experimenta de día a día? ¿Diría que tiene... | BRDIC4 |
| | Ningún control 5 Muy poco control..... 4 Una cantidad moderada de control 3 Bastante control 2 Extremo control 1 NO APLICA 8 | |
| 5. | ¿Cuánto control personal cree usted que tiene sobre el curso a largo plazo de su enfermedad; es decir, si mejorará o, al menos, no empeorará en el futuro? ¿Diría que tiene... | BRDIC5 |
| | Ningún control 5 Muy poco control..... 4 Una cantidad moderada de control 3 Bastante control 2 Extremo control 1 NO APLICA 8 | |
| 6. | ¿Cuánto control personal piensa usted que tiene sobre el cuidado médico y el tratamiento de su enfermedad? ¿Diría que tiene... | BRDIC6 |
| | Ningún control 5 Muy poco control..... 4 Una cantidad moderada de control 3 Bastante control 2 Extremo control 1 NO APLICA 8 | |

OBLIGACIÓN FILIAL

En esta siguiente serie de declaraciones le voy a hacer preguntas acerca de sus opiniones con respecto a la ayuda en el hogar.

1. Los hijos casados deben de vivir cerca de sus padres para proveer cuidado. ¿Está usted ...
Fuertemente de acuerdo 5
Un poco de acuerdo 4
Ni de acuerdo ni en desacuerdo 3
Un poco en desacuerdo 2
Fuertemente en desacuerdo 1
BRDFO1
2. Los padres no deben de contar con que sus hijos le hagan tareas. ¿Está usted ...
Fuertemente de acuerdo 5
Un poco de acuerdo 4
Ni de acuerdo ni en desacuerdo 3
Un poco en desacuerdo 2
Fuertemente en desacuerdo 1
BRDFO2
3. Los padres deben de contar con que sus hijos adultos les ayuden. ¿Está usted ...
Fuertemente de acuerdo 5
Un poco de acuerdo 4
Ni de acuerdo ni en desacuerdo 3
Un poco en desacuerdo 2
Fuertemente en desacuerdo 1
BRDFO3
4. Es el deber de un(a) hijo(a) ayudar a sus padres. ¿Está usted ...
Fuertemente de acuerdo 5
Un poco de acuerdo 4
Ni de acuerdo ni en desacuerdo 3
Un poco en desacuerdo 2
Fuertemente en desacuerdo 1
BRDFO4
5. Es preferible pagarle a un profesional para que ayude a proveer cuidado. ¿Está usted ...
Fuertemente de acuerdo 5
Un poco de acuerdo 4
Ni de acuerdo ni en desacuerdo 3
Un poco en desacuerdo 2
Fuertemente en desacuerdo 1
BRDFO5
6. Pagar por ayuda profesional significa que un pariente no está tomando responsabilidad. ¿Está usted ...
Fuertemente de acuerdo 5
Un poco de acuerdo 4
Ni de acuerdo ni en desacuerdo 3
Un poco en desacuerdo 2
Fuertemente en desacuerdo 1
BRDFO6
7. Es mejor dejar un trabajo para proveer cuidado que pagarle a un profesional. ¿Está usted ...
Fuertemente de acuerdo 5
Un poco de acuerdo 4
Ni de acuerdo ni en desacuerdo 3
Un poco en desacuerdo 2
Fuertemente en desacuerdo 1
BRDFO7

CES-D SCALE

Ahora le voy a leer una lista de formas en que usted se pudo sentir o en que se comportó durante la semana pasada. Cuando lea cada declaración, por favor dígame que categoría describe mejor cuán a menudo usted se sintió de esa manera **durante la semana pasada**.

| | Raramente O Ningún Tiempo (Menos que un día) | Alguna Tiempo (1-2 días) | Moderado Tiempo (3-4 días) | Siempre (5-7 días) | |
|---|--|--------------------------------|----------------------------------|-----------------------|----------|
| <i>Durante la semana pasada:</i> | | | | | |
| 1. Estuve molestanda por cosas que generalmente no me molestan. ¿Diría usted que se sintió de esta manera... | 1 | 2 | 3 | 4 | BRDCES1 |
| 2. No tuve ganas de comer; Mi apetito fue pobre | 1 | 2 | 3 | 4 | BRDCES2 |
| 3. Me sentí que no podía quitarme de encima la melancolía aún con la ayuda de mis amigas o familia | 1 | 2 | 3 | 4 | BRDCES3 |
| 4. Me consideré tan valiosa como la demás gente | 4 | 3 | 2 | 1 | BRDCES4 |
| 5. Tuve problemas manteniendo la concentración en lo que estaba haciendo | 1 | 2 | 3 | 4 | BRDCES5 |
| 6. Me sentí deprimida | 1 | 2 | 3 | 4 | BRDCES6 |
| 7. Me sentí que todo lo que hacía me costaba esfuerzo | 1 | 2 | 3 | 4 | BRDCES7 |
| 8. Me sentí con esperanza en el futuro | 4 | 3 | 2 | 1 | BRDCES8 |
| 8. Pensé que mi vida había sido un fracaso | 1 | 2 | 3 | 4 | BRPCES9 |
| 9. Me sentí temerosa | 1 | 2 | 3 | 4 | BRDCES10 |
| 10. Mi sueño fue inquieto | 1 | 2 | 3 | 4 | BRDCES11 |
| 11. Fui feliz | 4 | 3 | 2 | 1 | BRDCES12 |
| 12. Hablé menos de lo usual | 1 | 2 | 3 | 4 | BRDCES13 |
| 13. Me sentí solitaria | 1 | 2 | 3 | 4 | BRDCES14 |
| 14. Encontré que la gente no fue amistosa | 1 | 2 | 3 | 4 | BRDCES15 |
| 16. Disfruté de la vida | 4 | 3 | 2 | 1 | BRDCES16 |
| 17. Tuve episodios de llanto | 1 | 2 | 3 | 4 | BRDCES17 |

| | | Raramente O Ningún Tiempo (Menos que un día) | Alguna Tiempo (1-2 días) | Moderado Tiempo (3-4 días) | Siempre (5-7 días) | |
|-----|---|--|--------------------------------|----------------------------------|-----------------------|----------|
| 18. | Me sentí triste | 1 | 2 | 3 | 4 | BRDCES18 |
| 19. | Me sentí que no le gustaba a la gente | 1 | 2 | 3 | 4 | BRDCES19 |
| 20. | No pude animarme | 1 | 2 | 3 | 4 | BRDCES20 |
| 21. | Me sentí solitaria o apartada de los demás | 1 | 2 | 3 | 4 | BRDCES21 |

ESCALA DE ANSIEDAD ESTADO-RASGO (ESTADO MODIFICADO)
(STATE-TRAIT ANXIETY SCALE -- MODIFIED STATE)

Le voy a leer un número de declaraciones que han usado la gente para describirse. Al leerle cada declaración, por favor dígame la respuesta que describe como usted se siente en *este momento*.

| | | <u>De Ningún</u> <u>Modo</u> | <u>Un poco</u> | <u>Moderadamente</u> | <u>Muchísimo</u> | |
|-----|---|---------------------------------|----------------|----------------------|------------------|---------|
| 1. | Me siento calmada. ¿Diría usted que esto describe como se siente... | 1 | 2 | 3 | 4 | BRDST1 |
| 2. | Me siento segura | 1 | 2 | 3 | 4 | BRDST2 |
| 3. | Estoy tensa | 1 | 2 | 3 | 4 | BRDST3 |
| 4. | Me siento forzada | 1 | 2 | 3 | 4 | BRDST4 |
| 5. | Me siento tranquila | 1 | 2 | 3 | 4 | BRDST5 |
| 6. | Me siento desconcertada | 1 | 2 | 3 | 4 | BRDST6 |
| 7. | Actualmente estoy preocupada por posibles desgracias | 1 | 2 | 3 | 4 | BRDST7 |
| 8. | Me siento satisfecha | 1 | 2 | 3 | 4 | BRDST8 |
| 9. | Me siento asustada | 1 | 2 | 3 | 4 | BRDST9 |
| 10. | Me siento cómoda | 1 | 2 | 3 | 4 | BRDST10 |
| 11. | Me siento segura de mí misma | 1 | 2 | 3 | 4 | BRDST11 |
| 12. | Me siento nerviosa | 1 | 2 | 3 | 4 | BRDST12 |
| 13. | Me siento agitada | 1 | 2 | 3 | 4 | BRDST13 |
| 14. | Me siento indecisa | 1 | 2 | 3 | 4 | BRDST14 |
| 15. | Me siento relajada | 1 | 2 | 3 | 4 | BRDST15 |
| 16. | Me siento contenta | 1 | 2 | 3 | 4 | BRDST16 |
| 17. | Me siento preocupada | 1 | 2 | 3 | 4 | BRDST17 |
| 18. | Me siento confundida | 1 | 2 | 3 | 4 | BRDST18 |
| 19. | Me siento constante | 1 | 2 | 3 | 4 | BRDST19 |
| 20. | Me siento agradable | 1 | 2 | 3 | 4 | BRDST20 |

OBSTACULO FISICO
(PHYSICAL BURDEN)

1. Algunas personas experimentan esfuerzo físico relacionada con el cuidado de una persona enferma. *Desde el diagnóstico de su madre*, ¿cuánto esfuerzo físico diría usted que ha experimentado al cuidar de su madre?

BRDPB1

Muchísimo esfuerzo físico 4
Una cantidad moderada de esfuerzo físico 3
Un poco de esfuerzo físico 2
Ningún esfuerzo físico 1

2. *Desde el diagnóstico de su madre*, ¿ha sido llamada o ha tenido que levantarse alguna vez durante la noche para cuidar de su madre?

BRDPB2

Sí 1 (PREGUNTE A&B)
No 2

- A. ¿Cuántas veces ha sucedido esto desde el diagnóstico?

BRDPB2A

núm. de veces

- B. (SI LA RESPONDEDORA VIVE CON EL PACIENTE): En las noches que tuvo que levantarse para cuidar de su madre, ¿cuántas veces usualmente se levantó?

BRDPB2B

Una vez 1
Dos veces 2
De 3 a 4 veces 3
Cinco veces o más 4

3. *Desde el diagnóstico de su madre*, ¿Hasta qué grado le ha afectado el cuidado de su madre su energía en cuanto a sus actividades cotidianas regulares? ¿Diría usted que tiene...

BRDPB3

Tanta energía como antes 4
Un poco menos de energía 3
Algo menos de energía 2
Mucho menos energía 1

OBSTACULO DE TIEMPO
(TIME BURDEN)

1. Como resultado de su provisión de cuidado *desde el diagnóstico de su madre*,

| | <u>SI</u> | <u>NO</u> | |
|---|-----------|-----------|---------|
| a. ¿Ha reducido la <i>cantidad de tiempo</i> que ha dedicado a sus actividades cotidianas regulares | 1 | 2 | BRDTB1A |
| b. ¿Ha <i>logrado menos</i> de lo que ha deseado | 1 | 2 | BRDTB1B |
| c. ¿No hace sus actividades cotidianas regulares tan <i>cuidadosamente</i> como lo usual? | 1 | 2 | BRDTB1C |

OBSTACULO SOCIAL
(SOCIAL BURDEN)

1. ¿Cuán frecuentemente se siente como si no tiene suficiente tiempo para atender sus propios quehaceres hogareños? ¿Diría usted...

| | | |
|---------------------|---|--|
| Frecuentemente..... | 4 | |
| A veces | 3 | |
| Raramente | 2 | |
| Nunca..... | 1 | |

BRDSB1

2. *¿Desde el diagnóstico de su madre,* Hasta qué grado se le ha hecho difícil a usted establecer una rutina diaria y planificar actividades debido a la enfermedad de su madre?

| | | |
|-------------------------|---|--|
| De ninguna manera | 1 | |
| Solamente un poco..... | 2 | |
| Un tanto | 3 | |
| Muchísimo | 4 | |

BRDSB2

3. *¿Desde el diagnóstico de su madre,* Hasta qué grado le ha hecho la enfermedad de su madre reducir la cantidad de tiempo que pasa con otros parientes? ¿Diría usted...

| | | |
|-------------------------|---|--|
| De ninguna manera | 1 | |
| Solamente un poco..... | 2 | |
| Un tanto | 3 | |
| Muchísimo | 4 | |

BRDSB3

3. *¿Desde el diagnóstico de su madre,* Hasta qué grado le ha hecho la enfermedad de su madre reducir la cantidad de tiempo que pasa con otros parientes? ¿Diría usted...

| | | |
|-------------------------|---|--|
| De ninguna manera | 1 | |
| Solamente un poco..... | 2 | |
| Un tanto | 3 | |
| Muchísimo | 4 | |

BRDSB4

4. *¿Desde el diagnóstico de su madre,* Hasta qué grado le ha hecho la enfermedad de su madre reducir el tiempo que pasa con amistades, vecinos o conocidos? ¿Diría usted...

| | | |
|--------------------------------------|---|--|
| De ninguna manera | 1 | |
| Solamente un poco..... | 2 | |
| Un tanto | 3 | |
| Muchísimo | 4 | |
| SI ES OFRECIDO: Nunca hice esto..... | 8 | |

BRDSB5

5. ¿Hasta qué grado le ha hecho la enfermedad de su madre reducir actividades más allá del hogar tal como irse de vacaciones o aplicarse a un pasatiempo favorito?

| | | |
|--------------------------------------|---|--|
| De ninguna manera | 1 | |
| Solamente un poco..... | 2 | |
| Un tanto | 3 | |
| Muchísimo | 4 | |
| SI ES OFRECIDO: Nunca hice esto..... | 8 | |

BRDSB6

CARGA CON RESPECTO AL EMPLEO
(EMPLOYMENT BURDEN)

SI LA RESPONDEDORA NO ESTA EMPLEADA ACTUALMENTE, PASE A LA SIGUIENTE SECCION,
"CARGA FINANCIERA". A TODAS LAS DEMAS, PREGUNTE:

1. *Desde el diagnóstico de su madre*, ¿cuántos días diría usted que ha llegado tarde a su trabajo o ha tenido que salir antes de completar sus horas de trabajo debido a que su madre/padre se sintiera enferma y no podía estar sola, o debido a que tuviera usted que acompañarla al hospital o a una cita médica, o por tener que hacerle un mandado a ella/él?

BRDEB1

núm. de días

2. *Desde el diagnóstico de su madre*, ¿cuántos días ha tomado usted "por enfermedad", vacacionales o personales debido a la enfermedad de su madre tales como cuándo se sentía ella enferma y no le podía dejar sola, o por tener que acompañarla al hospital o a una cita médica, o hacerle un mandado?

BRDEB2

núm. de días

3. SI ALGUNOS DIAS, PREGUNTE: ¿Cuántos de estos días tuvo que tomar sin recibir pago?

BRDEB3

núm. de días

4. *Desde el diagnóstico de su madre*, ¿hasta qué grado le ha afectado su provisión de cuidado su habilidad para concentrarse en su trabajo, o le ha afectado en cualquier otra manera su habilidad para hacer una buena labor? ¿Diría usted...

BRDEB4

En sumo grado 4
En algún grado 3
En menor grado..... 2
De ningún modo 1
SI ES OFRECIDO: No aplica, es auto-empleada o
trabaja independientemente 8

5. *Desde el diagnóstico de su madre*, ¿hasta qué grado le ha creado problemas su provisión de cuidado con sus supervisores o compañeros de trabajo debido a sus ausencias del trabajo o a su pobre labor? ¿Diría usted...

BRDEB5

En sumo grado 4
En algún grado 3
En menor grado..... 2
De ningún modo 1
SI ES OFRECIDO: No aplica, es auto-empleada o
trabaja independientemente 8

CARGA FINANCIERA
(FINANCIAL BURDEN)

- | | |
|---|---------|
| <p>1. <i>Desde el diagnóstico de su madre</i>, Hasta qué grado le ha causado a usted la enfermedad de su madre dejar pasar oportunidades para mejorar su situación financiera tales como tener que rehusar un ascenso de puesto o promoción en su trabajo, no buscar fuentes adicionales de ingreso o dejar pasar oportunidades para un trabajo? ¿Diría usted...</p> <p style="margin-left: 40px;">En sumo grado 4</p> <p style="margin-left: 40px;">En algún grado 3</p> <p style="margin-left: 40px;">En menor grado 2</p> <p style="margin-left: 40px;">De ningún modo 1</p> | BRDFB1 |
| <p>2. Algunas personas encuentran que cuidar de alguien quien está enfermo puede afectarle <u>financieramente</u> sus hábitos y estilo de vida usual. <i>¿Desde el diagnóstico de su madre</i>, Cuánto le ha hecho cambiar la enfermedad de su madre <u>sus hábitos financieros</u> y estilo de vida a usted? ¿Diría usted que ha hecho...</p> <p style="margin-left: 40px;">Muchos cambios en su estilo de vida usual 4</p> <p style="margin-left: 40px;">Algunos cambios 3</p> <p style="margin-left: 40px;">Pocos cambios 2</p> <p style="margin-left: 40px;">Ningunos cambios en absoluto 1</p> | BRDFB2 |
| <p>3. La enfermedad frecuentemente causa problemas financieros. <i>¿Desde el diagnóstico de su madre</i>, Cuán serios son sus problemas financieros debidos a la enfermedad de su madre? ¿Diría usted...</p> <p style="margin-left: 40px;">Muy serios 4</p> <p style="margin-left: 40px;">Un poco serios 3</p> <p style="margin-left: 40px;">No muy serios 2</p> <p style="margin-left: 40px;">Ningunos problemas financieros en absoluto 1</p> | BRDFB3 |
| <p>4. <i>Desde el diagnóstico de su madre</i>, ¿ha tenido usted gastos adicionales debido al cuidado de su madre que no hubiera tenido de otro modo, tales como tener que pagar por comidas especiales o artículos domésticos para ella, o gastos adicionales de transportación o teléfono?</p> <p style="margin-left: 40px;">Sí 1 (PREGUNTE A)</p> <p style="margin-left: 40px;">No 2</p> | BRDFB4 |
| <p>A. <i>Desde el diagnóstico de su madre</i>, ¿aproximadamente cuánto dinero a gastado en estos gastos adicionales? ¿Diría usted...</p> <p style="margin-left: 40px;">Menos de \$50 1</p> <p style="margin-left: 40px;">\$51 a \$100 2</p> <p style="margin-left: 40px;">\$101 a \$200 3</p> <p style="margin-left: 40px;">\$201 a \$500 4</p> <p style="margin-left: 40px;">\$501 a \$1,000 5</p> <p style="margin-left: 40px;">Más de \$1,000 6</p> | BRDFB4A |
| <p>5. (Aparte de estos gastos), ¿A proveado usted algún apoyo financiero a su madre para ayudarle con los costos relacionados a su enfermedad <i>desde</i> _____?</p> <p style="margin-left: 40px;">Sí 1 (PREGUNTE A-C)</p> <p style="margin-left: 40px;">No 2</p> | BRDFB5 |

A. Desde el diagnóstico de su madre, ¿ha tenido usted que...

SI NO

Utilizar ahorros?..... 1 2

BRDFB5A1

Vender bienes tales como acciones o bonos, su casa, su automóvil, ensures domésticos mayores, propiedades de inversión o bienes raíces? (ESPECIFIQUE):

..... 1 2

BRDFB5A2

Tomar dinero prestado? 1 2

BRDFB5A3

B. Aproximadamente, ¿cuánto dinero de sus ahorros u otros bienes ha gastado usted hasta la fecha para cubrir los costos relacionados con la enfermedad de su madre desde el diagnóstico de su madre? Voy a leerle unas cifras. Hágame el favor de pararme cuando llegue a la categoría que incluye la cantidad que usted a gastado.

BRDFB5B

Menos de \$1,000 1
\$1,000 a \$3,000 2
\$3,001 a \$5,000 3
\$5,001 a \$10,000 4
\$10,001 a \$15,000 5
\$15,001 a \$20,000 6
Sobre \$20,000 7

C. ¿Diría usted que el dinero que usted contribuye ha sido...

BRDFB5C

Una gran privación financiera 3
Un poco de privación financiera 2
Ninguna privación financiera 1

6. Desde el diagnóstico de su madre, ¿ha tenido su madre algunos ayudantes a los cuales se le ha pagado, tales como una enfermera, ama de llaves o asistente de salud quienes fueron contratados para ayudarle debido a su enfermedad?

BRDFB6

Sí 1 (PREGUNTE A)
No 2

A. ¿Ayuda usted a pagar por esta ayuda contratada?

BRDFB6A

Sí 1
No 2

7. ¿Desde el diagnóstico de su madre, Ha habido alguna otra persona, tal como otros miembros de la familia o amistades quienes han ayudado a pagar por algunos de los costos relacionados con la enfermedad de su madre?

BRDFB7

Sí 1 (ASK A)
No 2

A. ¿Quién ha ayudado financieramente? Por favor, dígame que parentesco tiene con usted. (INDAGUE: ¿ALGUIEN MAS?)

Sexo

Parentesco a la Hija Quien Provee Cuidado

Varón

Hembra

..... 1 2
..... 1 2
..... 1 2

BRDFB7R1
BRDFB7S1
BRDFB7R2
BRDFB7S2
BRDFB7R3
BRDFB7S3

RED DE RELACIONES (ABREVIADO)
(NETWORK OF RELATIONSHIPS -- ABBREVIATED)

Nos interesa saber como la enfermedad cambia las relaciones. En la siguiente serie de preguntas, deseamos saber como ha sido la relación con su madre *desde su diagnóstico y como fue antes de su diagnóstico*.

| | | <u>De Ningún Modo o Poquito</u> | <u>Un poco</u> | <u>Mucha</u> | <u>Extrema- demente</u> | <u>Lo Máximo</u> | <u>DNA</u> | |
|----|---|---|----------------|--------------|-----------------------------|----------------------|------------|---------|
| 1. | ¿Cuánto se enojan usted y su madre una con la otra... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR1A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR1B |
| 2. | ¿Cuán satisfecha está usted con la relación entre usted y su madre... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR2A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR2B |
| 3. | ¿Hasta qué punto le cuenta usted todo a su madre... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR3A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR3B |
| 4. | ¿Cuánto le ayuda usted hacer cosas a su madre que ella no puede hacer por sí misma... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR4A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR4B |
| 5. | ¿Cuánto le trata su madre a usted con admiración y respeto... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR5A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR5B |
| 6. | ¿Cuánto difieren de opinión usted y su madre... | | | | | | | |
| | a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR6A |
| | b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR6B |

| | <u>De Ningún Modo o Poquito</u> | <u>Un poco</u> | <u>Mucha</u> | <u>Extrema- demente</u> | <u>Lo Máximo</u> | <u>DNA</u> | |
|--|---|----------------|--------------|-----------------------------|----------------------|------------|----------|
| 7. ¿Cuán feliz está usted con la manera en qué son las cosas entre usted y su madre... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR7A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR7B |
| 8. ¿Cuánto comparte usted sus secretos y sentimientos privados con su madre... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR8A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR8B |
| 9. ¿Cuánto protege y vela usted por su madre... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR9A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR9B |
| 10. ¿Hasta qué punto le trata su madre a usted cómo una personal hábil... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR10A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR10B |
| 11. ¿Cuánto discuten usted y su madre... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR11A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR11B |
| 12. ¿Cuán buena es su relación con su madre... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR12A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR12B |
| 13. ¿Cuánto habla con su madre sobre asuntos que no desea que otros sepan... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR13A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR13B |

| | <u>De Ningún Modo o Poquito</u> | <u>Un poco</u> | <u>Mucha</u> | <u>Extrema- demente</u> | <u>Lo Máximo</u> | <u>DNA</u> | |
|--|---|----------------|--------------|-----------------------------|----------------------|------------|----------|
| 14. ¿Cuánto cuida usted de su madre... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR14A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR14B |
| 15. ¿Cuánto le gusta o aprueba su madre de las cosas que usted hace... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR15A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR15B |
| 16. ¿Cuán apegada es su relación con su madre... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR16A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR16B |

| | <u>Madre Casi Siempre Hace</u> | <u>Madre Hace a Menudo</u> | <u>Casi Lo Mismo</u> | <u>Yo Hago a Menudo</u> | <u>Casi Siempre Hago Yo</u> | <u>DNA</u> | |
|--|------------------------------------|--------------------------------|--------------------------|-----------------------------|-------------------------------------|------------|----------|
| 17. Entre usted y su madre, ¿quién le dice a la otra lo que debe hacer con más frecuencia... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR17A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR17B |
| 18. Entre usted y su madre, ¿cuál de las dos tiende a ser la jefa en la relación... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR18A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR18B |
| 19. En su relación con su madre, ¿quién tiende a asumir el mando y decidir lo que se debe hacer... | | | | | | | |
| a. desde su diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR19A |
| b. antes del diagnóstico? | 1 | 2 | 3 | 4 | 5 | 8 | BRDNR19B |

ESCALA DE IMPACTO DEL EVENTO
(IMPACT OF EVENT SCALE)

Hace algún tiempo atrás su mamá fue diagnosticada con cáncer del seno. Yo voy a leerle ahora una lista de comentarios hechas por personas que están enfrentando en su vida situaciones de estrés similares. A medida que le voy leyendo cada comentario, piense sobre la enfermedad de su mamá y sus experiencias desde que le dieron el diagnóstico, y por favor dígame durante la semana pasada con que frecuencia ese comentario fue verdadero para usted.

| <i>Durante la semana pasada:</i> | <u>Nunca</u> | <u>Raramente</u> | <u>Algunas veces</u> | <u>Muchas veces</u> | |
|--|--------------|------------------|----------------------|---------------------|----------|
| 1. Yo pensé sobre esto cuando yo no quería. Diría usted que esto es verdad para ud... | 1 | 2 | 3 | 4 | BRDIES1 |
| 2. Yo evité ponerme triste cuando pense acerca de esto o me lo recordaron. | 1 | 2 | 3 | 4 | BRDIES2 |
| 3. Yo traté de sacarlo de mi memoria. | 1 | 2 | 3 | 4 | BRDIES3 |
| 4. Yo tuve problemas para dormir porque las imágenes y los pensamientos acerca de esto vinieron a mi mente. | 1 | 2 | 3 | 4 | BRDIES4 |
| 5. Yo tuve reacciones de sentimientos fuertes acerca de esto. | 1 | 2 | 3 | 4 | BRDIES5 |
| 6. Yo tuve sueños acerca de esto. | 1 | 2 | 3 | 4 | BRDIES6 |
| 7. Yo me aparté de lo que me recordara esto. | 1 | 2 | 3 | 4 | BRDIES7 |
| 8. Yo sentí como si esto no hubiera pasado o que no era real. | 1 | 2 | 3 | 4 | BRDIES8 |
| 9. Yo traté de no hablar de esto. | 1 | 2 | 3 | 4 | BRDIES9 |
| 10. Las imágenes de esto venían a mi mente. | 1 | 2 | 3 | 4 | BRDIES10 |
| 11. Otras cosas me mantenían pensando acerca de esto. | 1 | 2 | 3 | 4 | BRDIES11 |
| 12. Yo estaba conciente de que todavía tenía muchos sentimientos acerca de esto, pero yo no quise enfrentarme a ellos. | 1 | 2 | 3 | 4 | BRDIES12 |
| 13. Yo traté de no pensar acerca de esto | 1 | 2 | 3 | 4 | BRDIES13 |
| 14. Cualquier recuerdo me traía sentimientos acerca de esto. | 1 | 2 | 3 | 4 | BRDIES14 |
| 15. Mis sentimientos sobre esto estaban un poco confusos. | 1 | 2 | 3 | 4 | BRDIES15 |

PERCEPCIÓN DE RIESGOS DE CÁNCER DEL SENO
(PERCEIVED RISK OF BREAST CANCER)

1. En su opinión, comparada a otras mujeres de su edad, ¿cuales son sus posibilidades de coger cáncer del seno? Diría usted que son...

BRDPR1

Muy bajas1
Algo bajas.....2
Las mismas.....3
Algo altas.....4
Muy altas5

2. ¿Cómo el diagnóstico de cáncer del seno de su madre afecto su percepción acerca de sus posibilidades de desarrollar cáncer del seno? Diría usted que...

BRDPR2

No ha tenido efecto en mí.....1
Me hizo sentir algo más a riesgo2
Me hizo sentir mucho más a riesgo3

3. Comparada a otras mujeres con madres *con* cáncer del seno, ¿cuales son sus posibilidades de desarrollar cáncer del seno? Diría usted que son...

BRDPR3

Muy bajas1
Algo bajas.....2
Las mismas.....3
Algo altas.....4
Muy altas5

4. Comparada a otras mujeres con madres *sin* cáncer del seno, ¿cuáles son sus posibilidades de desarrollar cáncer del seno? Diría usted que son...

BRDPR4

Muy bajas1
Algo bajas.....2
Las mismas.....3
Algo altas.....4
Muy altas5

CUESTIONARIO DE CÁNCER DEL SENO
(BREAST CANCER QUESTIONNAIRE)

- | | |
|---|----------|
| <p>1. ¿Cuánto mide usted?</p> <p>_____pies _____pulgadas</p> | BRDCQ1 |
| <p>2. ¿Cuánto pesa usted?</p> <p>_____libras</p> | BRDCQ2 |
| <p>3. ¿Come usted 3 ó más porciones de vegetales al día? (<i>1 porción es más o menos una taza de hojas verdes crudas o dos tazas de otros vegetales crudos o cocinados.</i>)</p> <p>Sí 1</p> <p>No 2</p> | BRDCQ3 |
| <p>4. ¿Bebe usted usualmente 1 o más porciones de alcohol al día ? (<i>1 porción es una lata de cerveza, una copa de vino, o un "shot" de bebida fuerte.</i>)</p> <p>Sí 1</p> <p>No 2</p> | BRDCQ4 |
| <p>5. ¿Qué edad tenía usted cuando empezó a menstruar (tener el período)?</p> <p>Menor de 15 años 1</p> <p>Mayor de 15 años 2</p> | BRDCQ5 |
| <p>6. ¿Está usted actualmente tomando pastillas anticonceptivas?</p> <p>Sí 1</p> <p>No 2</p> | BRDCQ6 |
| <p>7. ¿Cuántos niños usted ha tenido (parido)?</p> <p>Ninguno 1</p> <p>Uno 2</p> <p>Dos o más 3</p> | BRDCQ7 |
| <p>8. ¿Qué edad tenía usted cuando tuvo (parió) su primer hijo?</p> <p>Menor de 35 años 1</p> <p>Mayor de 35 años 2</p> | BRDCQ8 |
| <p>9. ¿Ha usted amamantado (leche de pecho) por lo menos por un año?</p> <p>Sí 1</p> <p>No 2</p> | BRDCQ9 |
| <p>10. ¿Está usted en la menopausia?</p> <p>Sí 1</p> <p>No 2</p> | BRDCQ10 |
| <p>A. ¿Le empezó a usted la menopausia antes de los 55 años?</p> <p>Sí 1</p> <p>No 2</p> | BRDCQ10A |

(PREGUNTE A-C)

| | |
|---|----------------|
| B. ¿Está usted actualmente en terapia de reemplazo de hormonas? | BRDCQ10B |
| Sí 1 | |
| No 2 | |
| C. ¿Ha estado usted alguna vez en terapia de reemplazo de hormonas? | BRDCQ10C |
| Sí 1 | |
| No 2 | |
| 11. ¿Ha tenido usted alguna vez una enfermedad benigna del seno? | BRDCQ11 |
| Sí 1 | |
| No 2 | |
| 12. ¿Ha tenido usted alguna vez una biopsia del seno? | BRDCQ12 |
| Sí 1 | (PREGUNTE A-B) |
| No 2 | |
| A. ¿Cuántas biopsias del seno ha tenido usted? | BRDCQ12A |
| _____ (numero) | |
| B. ¿A qué edad le hicieron su primera biopsia? | BRDCQ12B |
| _____ (edad) | |
| 13. ¿Tiene usted alguna (s) hermana(s) que alguna vez hayan tenido cáncer del seno? | BRDCQ13 |
| Sí 1 | (PREGUNTE A) |
| No 2 | |
| A. ¿Cuántas de sus hermanas han tenido cáncer del seno? | BRDCQ13A |
| _____ (numero) | |
| 14. ¿Es su raza mayormente judía? | BRDCQ14 |
| Sí 1 | |
| No 2 | |
| 15. ¿Se examinará usted misma los senos mensualmente? | BRDCQ15 |
| Sí 1 | |
| No 2 | |
| 16. ¿Se hace usted mamografías regularmente? | BRDCQ16 |
| Sí 1 | |
| No 2 | |
| 17. ¿Aproximadamente, cuántos meses atrás tuvo usted su última mamografía? | BRDCQ17 |
| _____ (meses) | |

GRACIAS POR SU COOPERACION.
(THANK YOU FOR YOUR COOPERATION).

¿Existe alguna otra cosa sobre la cuál desea comentar qué no hemos cubierto en esta entrevista?

HORA DE CONCLUSION:

____/____ a.m./p.m
hora minutos

BRDHR
BRDMN

INTERVIEWER REMARKS

- | | |
|--|--|
| <p>1. Did respondent experience or exhibit emotional or psychological problems during the interview?</p> <p>Yes 1 (ANSWER A) No 2</p> <p>A. What was the problem? _____ _____ _____</p> | <p>BRDR1</p> <p>BRDRA1 BRDRA2 BRDRA3</p> |
| <p>2. Were there any other problems during the interview?</p> <p>Yes 1 (ANSWER A) No 2</p> <p>A. What was the problem? _____ _____ _____</p> | <p>BRDR2</p> <p>BRDR2A1 BRDR2A2 BRDR2A3</p> |
| <p>3. Was interview conducted in English or Spanish?</p> <p>English 1 (ANSWER A) Spanish 2</p> <p>A. How much trouble does respondent have understanding English?</p> <p>None 1 Some 2 A great deal 3</p> | <p>BRDR3</p> <p>BRDR3A</p> |
| <p>4. Regardless of whether or not interview was completed in one session, did the respondent <i>want to</i> terminate interview before interview was finished?</p> <p>Yes 1 (ANSWER A) No 2</p> <p>A. At what points and why? _____ _____ _____</p> | <p>BRDR4</p> <p>BRDR4A1 BRDR4A2 BRDR4A3</p> |
| <p>5. Did respondent need to complete interview over two or more sessions?</p> <p>Yes 1 (ANSWER A) No 2</p> <p>A. Reasons given for needing to break up interview _____ BRDR5A1 _____</p> | <p>BRDR5</p> |

6. Date interview started:

____/____/____
(mo) (da) (yr)

BRDR6MO
BRDR6DA
BRDR6YR

7. Date interview completed:

____/____/____
(mo) (da) (yr)

BRDR7MO
BRDR7DA
BRDR7YR

8. Number of interviewing sessions needed to complete interview:

One 1
Two 2
Three 3
Four 4

BRDR8

9. Name and ID of interviewer:

NAME I.D.

BRDR9

10. Total time spent interviewing:

____/____
hours minutes

BRDR10

Interviewer Comments and observations not otherwise specified:

APPENDIX H

Focused Interview Topic Guide

Topic Guide

Topics to be discussed with the caregiving daughter during the focused interview:

A. Diagnosis, illness and treatment:

- (A.1) Circumstances leading to mother's diagnosis
- (A.2) Daughter's/family's reactions to mother's diagnosis
- (A.3) Daughter's/family's reactions to mother's illness and treatment experiences
- (A.4) Daughter's perception of changes in relationship with mother since diagnosis

B. Cancer Risk

- (B.1) Daughter's perceived vulnerability to cancer
- (B.2) Daughter's perception of personal risk factors
- (B.3) Daughter's informal support experiences
- (B.4) Daughter's formal support and/or counseling experiences
- (B.5) Medical assessment, guidance, information
- (B.6) Health concerns about the future
- (B.7) Health monitoring plans

C. Caregiving:

- (C.1) Circumstances leading to daughter's assumption of caregiving
- (C.2) Daughter's levels and extent of caregiving since diagnosis
- (C.3) Daughter's assessment of mother's support needs
- (C.4) Daughter's perception of caregiving ability and performance since diagnosis
- (C.5) Daughter's needs for support and assistance with caring for mother
- (C.6) Caregiving burden
- (C.7) Positive aspects of caregiving
- (C.8) Attitudes towards caregiving responsibilities

D. Lifestyle Changes

- (D.1) Change in family roles and functioning since illness
- (D.2) Impact of illness and caregiving on relationship with family, friends
- (D.3) Impact of illness and caregiving on work
- (D.4) Future goals, plans
- (D.5) Impact of illness and caregiving on quality of life

Specific Questions to Include:

1. Has dealing with your mother's breast cancer caused changes in major life events: fertility issues, child rearing, fears for your children's risk of cancer?
2. In addition to taking care of your mother, are there other members of your family who require your care and assistance (such as children, other elderly or sick relatives)? If yes, ask relationship to respondent and type of help needed from respondent.